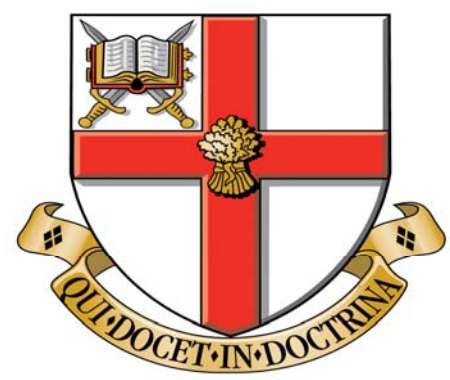

University of Chester

In the context of health care, where is God in the dark places of human experience?: Implications for Pastoral Care.

Thesis submitted in accordance with the requirements of the University of Chester for the degree of Doctor of Professional Studies in Practical Theology

by

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May 2013

Acknowledgements

I wish to record my grateful thanks to the following people: Jackie Skeel in helping to process my application to interview patients through my local NHS Research Ethics Committee; Terrie Burland in typing up the Interview Transcripts; two former chaplaincy colleagues, the Rev'd Grenda Hurt and the Rev'd Michael Johnston for proof reading the first draft of the dissertation text; Ann Lewin for her detailed proof reading of its final draft; Samuel Cousins in producing a printed copy of 'Collage'.

I also wish to thank my two academic supervisors, Professor Elaine Graham and Prebendary Dr. Peter Speck, whose unstinting encouragement gave me the confidence, not only to attempt, but to bring to effect this reflection on health care praxis.

Finally, I wish to thank by wife Robbie, who kept faith in me when I came close to losing faith in myself and gave me the time and space to bring this task to its conclusion.

Diagram and Table index

Dissertation Abstract

Triggered by a chance pastoral encounter with a nurse who articulated a sense of the presence of God in the midst of existential darkness, this study seeks to explore two underlying questions: “In the context of health care, where is God in the “dark places” of human experience”? and “How is that experience discerned and communicated to others?” It will show how a greater understanding of these questions will add value to the provision of pastoral care in the health care environment by enabling a tailored intervention to be offered that will be to the benefit of the patient and their clinical and pastoral outcome. The research uses insights gained from academia, including theological and health care literature, to explore the former, and a musicological review to explore the latter. These are set alongside qualitative material in the form of case studies and taped interviews.

Whilst this study suggests that credible belief in God is possible if God can be seen to be involved with, and supportive of, humanity in the midst of its suffering, it also shows that the way that experience is discerned and thus communicated to others, involves a process of listening and performing comparable with the act of music-making. As with its musical counterpart (incorporating elements of melody, rhythm, dynamics and timbre), this research maintains that the process of pastoral listening and performing is also multi-faceted, existing on a number of different levels. An awareness of these enables the pastoral encounter to begin to be rooted in a process of meaning-making analogous with wisdom emerging out of lament. This research further suggests that one way such wisdom can be discerned is in the way that the lament within the pastoral encounter is itself framed, using musical form as one way of holding in relationship the tradition of faith with pastoral praxis.

In using specific examples of music-making as a guide to effective pastoral care, this study concludes with recommended pastoral interventions pertaining to the pastoral practice of healthcare chaplaincy, advocating that through *reclaiming the spiritual space* and *reframing the pastoral encounter,* it is still possible for chaplains *to model the presence of God.*

“I will give you the treasures of darkness and riches hidden in secret places” (Isaiah 45: 3 [NRSV]).

Summary of Portfolio

Arising from my role as a hospital chaplain, and being interested in whether meaningful dialogue is possible between clinicians and theologians, **my Literature Review** began to explore the relationship between Clinical Theology and the wider pastoral care and counselling movement within the UK. It concluded by finding that Clinical Theology still has much to contribute in a post-modern world, and offers the hope, most especially, for fragmented personalities / organisations, that some kind of integration is possible but only when it takes seriously the need firstly to understand which aspect of Christ speaks to where people find themselves. This study laid the groundwork for exploring Christ as the light present within the darkness which is addressed in my Dissertation.

My Publishable Article started from the premise that health care chaplaincy is in crisis, having to serve two masters: church and hospital, religious and secular. In an attempt to discover where, how and what kind of connections could be made between these I explored whether chaplaincy should seek to follow a more vocational path within its faith community or a more professional path within health care. By correlating material from an article by Tony Dyson first published in the early 1980s, with that from more contemporary chaplaincy sources, I considered how the former might inform the latter and assist health care chaplaincy rediscover its theological roots.

Arising out of my need as a hospital chaplain, to ground my theology in contextual practice, **my Reflection on Practice** considered my encounters with one particular mental health in-patient (A) which took place over a period of nine months at the hospital in which I worked. Using both historical and contemporaneous accounts of my pastoral contacts with this patient, because her story contained much metaphorical pathologising, I considered whether biblical metaphor might help frame and give voice to her encounter with that which appeared to lie beyond words. In my Dissertation I extend the idea of metaphor to consider music as a means of framing and giving voice to the pastoral encounter.

My Research Proposal put together a structure for exploring how God might be experienced as being present (or absent) for those responding to difficult periods of illness or loss. The objective of my research has been to develop a better understanding of the theological underpinnings of more effective chaplaincy provision. As so often the language that is employed to communicate both the divine and episodes of existential darkness is that of symbol and metaphor, this proposal set out a rationale for interrogating a sample of musicians and relevant musical compositions to see if their testimonies had anything helpful to offer pastoral practice by way of communicating and discerning the presence of God.

Introduction

Within a few months of being appointed to my present hospital chaplaincy post, I was called to Intensive Care in the middle of the night by the ward sister to see a member of staff. The nurse in question seemed to be having some kind of breakdown. Alone with her in the relatives' room, there were periods where we sat in silence and when she talked and cried. Things were going wrong in her family, she seemed to be having a crisis in her faith, having been all her life a devout Roman Catholic. She was finding it hard to pray because she wasn't sure where God was for her any more. I asked her whether she had any sense of there being a light shining in her darkness. She said that she could see no light at all. But in the darkness she did admit to sensing a benign presence. The darkness, although being total and very real, did not for her signify a total absence of God. The realisation that God was in her darkness, as she was to tell me some months later, was the beginning of that member of staff's journey back to faith. It also had a profound effect on me.

Whilst hospital chaplains come alongside many people in the dark places of human experience, it was the encounter with this member of staff that led me to reflect upon its implications for my praxis and journey of faith, and which has in turn led to me undertaking this research. It has challenged me to explore what is meant by: God; dark places of human experience in general; and within health care in particular; and to search for an appropriate language in which to express this when traditional ways of speaking about

God appear not to be sufficient.

Whilst taking note of Turner's observation that mediaeval writers discern the mystical outside rather than within human experience (Turner, 1995, p.4), in my research, I will explore where God is in the dark places of human experience for me as a hospital chaplain, for the patient and for members of staff. I will look at how loss in general and bereavement in particular is experienced within the context of health care and its theological significance particularly in the light of the cross. But I am also interested in the language that people use to communicate God's presence or absence in their own dark experiences. As language arising out of experiential darkness so often seems to be that of symbol and metaphor, I shall explore whether the artistic language of music, especially the musical device of "Collage", in providing "a wider theoretical context in which the experience can be understood", has anything helpful to offer pastoral care by way of providing specific examples of good pastoral practice (Pattison and Lynch, 2005, p. 411). Paying attention to the absence of God, I will consider whether anybody, and especially a chaplain, can model the attractiveness of God at such a desolate time.

My research will use insights gained from academia, including a theological and health care literature review and a musicological review. The theological literature considers examples arising out of incarceration, ethnic cleansing,

abuse, suffering and lament. The health care literature looks at examples from bereavement, change, disability and dementia. The musicological material explores compositions arising out of the Second World War and social fragmentation. Because I have chosen to contextualise “the dark places of human experience” within health care, my research will also use insights gained from taped interviews with individuals taken from two groups of people (Christian leaders in public life and those who were patients at the time of being interviewed) and my own case studies. These will be set alongside a third interview group consisting of musicians, which looks at how dark experiences can be communicated and worked with through the medium of music. All of these will be subject to qualitative analysis.

Thus, adopting characteristics of practical theology identified by Pattison and Lynch, this study incorporates “reflection upon lived contemporary experience”, engages in “critical dialogue between theological norms and contemporary experience”, employs, through the use of music as a dialogue partner, “an interdisciplinary approach”, and reveals “the need for theoretical and practical transformation” within healthcare chaplaincy (Pattison and Lynch, 2005, p.410 - 411). The term “Collage” is usually used to describe a creative process in which various, often contrasting, materials are juxtaposed to form a new work of art. In this thesis I shall use it to describe the setting of received tradition alongside practical experience, which, in turn, advocates a model of theology in which “critical dialogue” and “theological reflection” generate “new insights” (Pattison and Lynch, 2005, p. 412, 415 – 418).

Furthermore, encouraged by Fisher and Phelps who have used the structure of a play as a suggested format for a thesis (2006), and Stevenson-Moessner who used an orchestra in concert as a metaphor for Practical Theology (2008), I am also borrowing a form from the world of classical music - Sonata Form with its threefold sections of Exposition, Development, and Recapitulation - as a way of holding in relationship contrasting material as structure for this dissertation.

The Exposition, is the section in which the initial themes are stated and enfolds the first two chapters: The Theological Literature Review (Chapter 1), The Clinical Literature Review and selected case studies (Chapter 2)

The Development section contains the Research Study (Chapter 3), the central chapter of this thesis, in which these initial themes are worked through and pulled apart. This section also contains a Musicological Review. (Chapter 4).

The Recapitulation, in which these themes emerge anew, embraces the final three chapters: Synthesis (Chapter 5), Questions for Pastoral Care (Chapter 6) and Recommendations for Pastoral Practice (Chapter 7).

Thus, arising out of an initial pastoral encounter, my research investigates the kinds of language and metaphor used by people who are experiencing times of existential difficulty in hospital by setting these alongside the kinds of language and metaphor used in a selection of other situations in which people have experienced episodes of metaphysical darkness. My hypothesis is that, within the hospital setting, this has a considerable influence on

patients' articulation of pastoral and spiritual needs, and that a greater understanding of this, drawn from first-hand experience, will add value to the provision of pastoral care in the health care environment by enabling a tailored intervention to be offered that would be to the benefit of the patient and their clinical and pastoral outcome.

Exposition

Chapter 1

God in the darkness – Theological Literature Review

Introduction

"Where and how is God discerned in the 'dark places' of human experience?" In exploring the topics of: darkness; suffering; sin and evil; surviving; human courage; the nature of God and that which gives life meaning; in this chapter I shall argue that the only way that God can be believed in with any credibility is if God can be seen to be involved with, and supportive of, humanity in the midst of its suffering, even when that involvement and support is voiced in a wisdom born of personal suffering in the form of a lament.

God with us

Sheila Cassidy, writing from the twin perspectives of a palliative care consultant familiar with helping others in periods of existential darkness, and as a former political prisoner who suffered torture whilst she was incarcerated, provides a helpful starting point. At the end of her book "Sharing the Darkness", in the process of engaging in "critical dialogue between theological norms and contemporary experience" (Pattison and

Lynch, 2005, p.410 - 411), she asks the question “How can we believe in a God who allows suffering?” She offers four possible suggestions:

1 There is no God and things just happen in a random way;

2 God is unable to control the elements in the world that he has created;

3 God can control them but chooses not too;

4 “God is somehow *involved* in every person's life and actually *arranges* that some people suffer more than others because it is part of his great cosmic plan” (author’s italics) (Cassidy, 1988, p. 156-7).

(Points 2 and 3 above are further developed by Pailin who explores the concepts that either “God is not all powerful” or “God is not wholly benevolent” (Pailin, 1992, p. 39)).

It is clear that Cassidy favours the fourth point. In a world, indeed in a universe, which is always changing, there will always be growth and decay just as there will always be birth and death. Suffering simply is. It exists because it is an integral part of the world as it has been created. To eliminate suffering would result in changing the universe as we presently perceive it, indeed to such an extent that we may not be present to perceive it at all (see below Hick, 1966, p. 9, 10). But what concerns Cassidy, as it will concern every person (with a faith or not) working in health care, is the sheer degree of suffering that some patients find themselves experiencing, and our apparent inability to mitigate it in any meaningful way. For Cassidy, as for anybody who has undergone any kind of suffering in their own life,

ministering to the sick puts each of us in touch once again with our own brokenness and vulnerability. Indeed, she sees the vulnerability of the carer as having a catalytical quality when she recognises that "We are all wounded and...we all contain within our hearts that love which is for the healing of the nations" (Cassidy, 1988, p. 3). This is what Lambourne means when he says, "He only is whole who is joined to the suffering of others." (Lambourne, 1963, p. 162)

At the bedside, patients frequently ask, "What have I done to deserve this? Why is God punishing me in this way? Why won't God heal me? Why do bad things happen to good people?" (Interestingly Kushner believes that the key question should not be "Why do bad things happen?" but "Where will we find the resources to cope when they do happen"? (Kushner, 2002, p. xv)). These theological questions demand a better response from the chaplain than "I don't know." Otherwise the chaplain can appear as impotent or irrelevant as the God he/she purports to represent. But giving patients answers born out of too much certainty can be equally unhelpful.

J.B Phillips (1969) has contended that for many people, their view of God has not progressed as they have physically and mentally developed. Their evolving concept of God has not been a continuous process and has become stuck. For them, "God is too small," and has become boxed in. Writing from a psycho-analytical perspective, Rizutto believes that which is

key to this process beginning, for good or for ill, is “the role of the parents in the formation of the representation of God” in the child (Rizutto, 1981 p. xiii). That which is key to this process developing is an understanding that “we create our own gods from the apparently simple warp and woof of everyday life”. There comes a point when this personal God comes into dialogue with the God of received tradition when the “God of religion and the God of the child-hero face each other”. The aging process in general, and awareness of one’s mortality in particular, is when “the existence of God becomes a personal matter to be faced or avoided” (Rizutto, 1981 p. 5 - 8).

Writing post Hiroshima, Garrison believes that for an increasing number of people, “the notion of God is inadequate in a secular world ‘come of age’” (Garrison, 1982, p.3). Writing from the feminist perspective, Soskice maintains that this language of inadequacy has been compounded by the “gendered imagery” surrounding God which has been seen negatively (Soskice, 2007, p. 4). Phillips has advocated a “letting go” of these fixed ideas of God, to allow our view of God to become much more fluid. Having done that, how we should focus our thoughts about God would be found in the person of Jesus Christ as “the Word made flesh”. The danger of course is that rather than seeing Jesus as a focusing of the un-focusable God, one could view him as another God-limiting concept, exclusively belonging to, and interpreted by, one particular group and not another, found only in the light of certainty and never in the darkness of exploration and enquiry .

Garrison believes that “what is required is a new conceptualization of both humanity and divinity”, in order to discover afresh “Emanuel ‘God with us’” (Garrison, 1982, p.3). McFague believes that this new conceptualization is best achieved through rediscovering the metaphorical language that lies at the heart of, and continually challenges, conceptual thinking (McFague, 1982, p. 25-26). Rizutto locates this language in “transitional space”, that place where “play and illusion,” “art culture and religion belong”, which she believes are essential for “psychic reality” (Rizutto, 1981 p. 209). In terms of speaking about God, this language is provisionally relational . (McFague, 1982, p. 194). Developing this point, Soskice advocates a view of God focusing on kinship which, whilst saying something “not only about God but about us…reawakens us to the promise of what we may become” (Soskice, 2007, p. 2, 3). This intimate relationship of God and humanity better enables God to be seen to be involved with, and supportive of, humanity in the midst of its suffering. In viewing God as “a representational object” Rizutto has shown that understanding a person’s view of God helps us better to understand the person and therefore enables us better to support them in moments of crisis (Rizutto, 1981, p. 8).

If the patient views God as being involved in their suffering, as supporting them and holding their hand, perhaps assisted by the chaplain acting “in loco Deus”, they may well discover, in the middle of their suffering, a sense of God's presence rather than being convinced of his absence. Patients seem to be in no danger of muddling up God with his representative. In talking

specifically of the dying patient, Cassidy says, the patients “know we are not God... All they ask is that we do not desert them” (Cassidy, 1988, p. 64). For the patient, *where* God is/isn't has a profound effect upon *who* God is/isn't and vice versa.

Where and who God is for a person also affects how they experience suffering by placing it within a wider context than simply locating it within the immediate experience. Suffering in the form of sickness has been described by Wilson as “a learning situation, a crisis event, and an opportunity for progress or regress” (Wilson, 1966, p. 18). Indeed suffering can even be a vehicle that can provide moments of revelation. Adalbert Stifter reports, “Pain is a Holy Angel which shows treasure to a man which otherwise remains forever hidden” (quoted in Cassidy, p. 87). For some, continued suffering may confirm in them a sense of fatalism and induce them simply to give up, for others it can induce in them “a letting go in order to grow and be free” (Cassidy, 1988 p. 95).

It is clear from the above that the caring presence of another helps a person who is suffering, indeed such a friendship can help in the “resurrection of the person” (Swinton, 2000, p.10). The presence of such a companion can provide a way for them to sense the presence of God. If God can be sensed as being present in the midst of, and even of sharing in a person’s suffering, it is capable of being experienced not as the absence of God but a voyage of

discovery into how God might be present, maybe even as “a pilgrimage” (Wilson, 1966, p.86).

1 Darkness

Perhaps the best exponent of discovering, in the midst of suffering, a sense of God's presence rather than being convinced of God’s absence, is St. John of the Cross. Whilst he was still in prison in Toledo, John wrote an initial eight stanza poem (each stanza of which consists of five lines each, the 40 lines of the poem giving a Lenten feel to the whole venture), which began to explore how humankind might aspire to union with God, how humankind might move from meditation towards contemplation (St John of the Cross, 2003, p. 1-2, 24-25) [Appendix 1]. He further reflected on these in two subsequent works: *The Ascent of Mount Carmel*, in which he comments on the active role of humankind in this process; and in *The Dark Night of the Soul* on the passive role of God. Whilst John writes in a time when a Christian faith would be assumed, his relevance to subsequent generations, including our own, is his continual wrestling to find an authentic and honest way to speak about his experience of God at work, even when God appears to be absent.

It is clear from his poem, and his reflections upon it, that John sees darkness, not as an experience to be feared, but as a place where God makes space in our lives to receive him. Darkness is an essential prerequisite for this new life to take root. His experience of God in the midst

of his imprisonment was that of darkness, in which “the only alternatives are a Spirit who fills, or chaos” (Matthew, 1995, p. 10). In the middle of the darkness, John senses “a certain companionship and strength which bears it company and so greatly strengthens it” (St John of the Cross, 2003, p. 70). But before one can apprehend this companionship, there must be space made for God to come in to our lives. This space can be experienced as emptiness. For John, “Absence of insight or feeling – even if it leaves the person 'in dryness, in darkness, feeling abandoned' – does not certify that God is any further away.” (Canticle, 2nd Redaction, 1.4 cited in Matthew, 1995 p. 32). Furthermore, “If God is beyond us, his approach is also liable to leave us feeling out of our depth” (Matthew, 1995, p. 56) It is God himself that “undertakes to create that space...He calls it 'night'” (Matthew, 1995, p. 51).

Darkness is used by John as a very rich metaphor, capable of a variety of meanings. Darkness can feel restrictive and prison-like. But, paradoxically, it can also be regarded as bringing with it clarity of vision, free from the distractions of the light-polluting day. The perceived absence of God can make God appear dark because we simply cannot compute his brightness, “our field of vision” being “too narrow” (Matthew, 1995, p. 104). Turner, with his interest in negative metaphors, concurs, believing “as the soul ascended to God it would approach a source of light which, being too bright for its powers of reception, would cause in it profound darkness” (Turner, 1995, p. 3).

Matthew comments that the symbol of night, through its spaciousness and clarity of vision, “is able to carry humanity's pain, able to hold even such a sense of alienation from God that the inner self feels dismantled... (But) it is able also to hold the 'spiritual resurrection'”. Darkness is the time of “letting God be who he is” (Matthew, 1995, p. 56). Communion with God is to be experienced through contemplation, which John describes as being “naught else than a secret, peaceful and loving infusion from God, which, if it is permitted, enkindles the soul with the spirit of love” (St John of the Cross, 2003, p. 27). This inrush of the God of love into our lives, Matthew goes on to describe as “His love felt (by us) as pain.” (Matthew, 1995, p. 57) But, Garrison points out, there is an irony here. Whilst “we can only successfully deal with the darkness in God if we have adequately integrated the light side of God”, the very search for God within darkness can appear to increase rather than lessen that sense of darkness (Garrison, 1982, p.200). “To seek God is like holding a light in the darkness. As the light increases, the circumference of the darkness also expands. The more light, therefore, the more darkness.” (Garrison, 1982, p.8)

It seems that what John of the Cross is saying is that night can be regarded as that time when nothing happens, a kind of non-time. Or it can be a time when horrors that remain hidden during the day suddenly bubble to the surface. It can also be a time of revelation. For many patients, coming into hospital can be a time of dislocation, a time when the normal bearings of life

are thrown out of kilter and even lost touch with altogether. For those *with* faith, this period of darkness can provide an opportunity for God's Spirit to fill their lives afresh. For those *without* faith, perhaps what John has to say is about simply being open to the possibility of something positive coming out of something negative.

Bonhoeffer**,** speaking out of the dark experience of being imprisoned by the Nazis for his part in a failed attempt to assassinate Hitler, comments that what compounded this dark experience for him was the uncertainty as to what the outcome of his period of incarceration might be. At times he believed that he would be released, at other times that he would die in prison. This uncertainty clearly shaped letters written in prison, as did the need to bolster the spiritual strength of those to whom he was writing. Bonhoeffer's uncertainty as to what the outcome of his own incarceration might be resonates well with patients in hospital. For the patient the abiding question, with its subsidiary, is “Will I be able to carry on as before or is there to be a change as to how I live my life day by day? If I won't, what are the new rules of engagement?” Patients vary as to how they deal with this uncertainty. Some will find themselves disabled by it and require much support; others, like Bonhoeffer, will worry as to the effects that this uncertainty may have on their nearest and dearest (see Chapter 3, p. 93 - 96 below).

2 Suffering, Sin and Evil

At the centre of any dark experience lies the amount of suffering that one may be undergoing, whether this be physical, psychological or spiritual in origin. But what actually is suffering? In an attempt to understand the nature of suffering, Hick distinguishes this from pain. Whilst “pain is…..a specific physical sensation” which, he acknowledges, often leads to suffering, he defines suffering as “that state of mind in which we wish violently or obsessively that our situation were otherwise” (Hick, 1966, p. 354-355). Because of this lack of contentedness with, and acceptance of the situation that the suffering person finds themselves in, Hick believes that suffering therefore can be seen as “a function of sin”. For surely “we should be able to accept our life in its entirety as God's gift and be free from anguish on account of it” (Hick, 1966, p. 355). Within the hospital situation this position is fraught with difficulty as it can encourage fatalism rather than perseverance in patients, and judgement rather than compassion in others. Allowing for the fact that for the person experiencing extreme and acute pain, the only resolution to their suffering will come about through effective and immediate pain relief, Hick is of the opinion that there are other occasions when “What makes illness...an experience of suffering is very often not pain as such but other elements in the situation.” (Hick, 1966, p. 356) Lambourne for example, locates suffering (as it is manifest in sickness) and sin sociologically, believing that both “are symptoms of communal disorder” (Lambourne, 1963, p.vii). But Hick goes on to say that just as “it is certainly

a great mistake to underestimate the extent of human suffering.....it is also a great mistake to underestimate the extent of human happiness and hope" (Hick, 1966, p. 357). The truth of the matter is that "bane and blessing" exist side by side. One cannot "remove the possibility of one without at the same time forfeiting the possibility of the other" (Hick, 1966, p. 363).

Locating this theme in a biblical perspective, in talking of Job, Ford describes him as continually vacillating between the twin poles of "bane and blessing", blessing and cursing. He notes how, in the midst of Job's affliction, God can seem very far away indeed. In the book of Job, Ford points out, Job's anxiety, particularly strong in Chapter 3 is balanced with, and transformed by, God's speaking from the whirlwind in Chapters 38 – 41. In this context, Job's suffering is not denied but is perceived in a different way, in a way that brings blessing, as indeed is creation which "is described as of significance in itself, not just in relation to humanity". Both are set within the context of infinity in which "the sheer glory of being is celebrated". So too, patients with faith whilst not denying their suffering, can perceive their suffering in a different way. Put simply, death cannot extinguish existence (Ford, 2007, p. 113).

For St. John of the Cross, also placing it within this wider context, suffering is seen as growing pains, maturation accompanying a period of growth. John uses the picture of a mother's evolving relationship with her child to make

this point; which Matthew summarises as: “a mother weaning a child so he may grow; a mother picking up a child, so he, and she, might actually get somewhere” (Matthew, 1995, p. 79). So Matthew would seem to be saying that, for John suffering is not an example “of God's withdrawal, but of his maternal love drawing closer” (Matthew, 1995, p. 80). Furthermore. “it is when you understand him (God) less clearly, that you are coming closer to him” (Canticle 2nd redaction 1:12 cited in Matthew 1995 p. 97). Be that as it may, that might not be how it is perceived by the sufferer themselves, and only achievable in hindsight from the objective position of wellness.

The problem with suffering for Hick is not that it exists, but that “instead of serving a constructive purpose, pain and misery seem to be distributed in random and meaningless ways, with the result that suffering is often undeserved and often falls upon men in amounts exceeding anything that could be rationally intended”. Hick's response as to why there is evil in the world is honestly to admit that he has no theory “to offer that would explain in any rational or ethical way why men suffer as they do. The only appeal left is to mystery” (Hick, 1966, p. 369). Garrison believes that at the root of this mystery lies the realisation that, “because of the demise of theism in the modern era”, not only have Christians “not had an adequate concept of God to bear witness to, they have also not had an adequate concept of the objective reality of evil” (Garrison 1982, p.21). In other words, evil must be understood as being real and capable of identity in its own right over and above the perversion of good. But it is vital to understand that both good and

evil exist subjectively within ourselves. To objectify evil as only existing within others undergirds and fuels ethnic cleansing and child abuse (Volf, 1996, p.79 and McFadyen, 2000, p. 195).

Garrison goes further when he argues that evil like good comes from God, that God creates and uses moral evil, that evil can be ultimately creative when it is used by God for a greater good, for example crucifixion (Garrison 1982, p.21). Hick like Garrison sees the element of mystery not only in a negative but also a positive light. It's not so much a question of just "seeing through a glass darkly" now, but also believing that there will come a time when "we shall see face to face'" (1 Cor. 13: 12 [RSV]). Hick and Garrison locate the existence of pain and suffering within an eschatological perspective (as indeed does Cassidy in point 4 above (p. 16)), understanding the existence of both as being crucial to "soul making" (Hick, 1966, p. 369 - 370), that resurrection process "in which human beings will be raised to life in the new kingdom" (Swinton, 2000, p. 130 -131). As Young says of humanity, it is work in progress, striving towards "a perfect ideal…being made in the image of God" (Young 1990, p. 189, 192). But the mystery of God, paradoxically expressed, remains.

When a patient's reality is a world of pain and suffering, there is always the danger of those who are well forgetting the reality of the unwell. To talk of suffering being an indication of "a function of sin" in the world, certainly at

one level, needs to be roundly challenged lest the patient somehow thinks that their suffering is a punishment for past wrongdoing (and what that would say about the kind of God that would use suffering as a form of punishment). What also needs challenging is the assumption that “we should be able to accept our life in its entirety as God's gift and be free from anguish on account of it” which smacks of fatalism (Hick, 1966, p. 355). This remains the case, even if the sinfulness from which humanity is being redeemed, and the human suffering which flows from that sinfulness, have in their own paradoxical way a place within the divine providence” (Hick, 1966, p. 359). But if Lambourne is right, and sickness and sin are communal in origin, Wilson maintains that whereas cure for the patient might be seen as “*restoration to function in society*”, healing, set within this wider context, can mean “*restoration to purposeful living in society*” (author’s italics) (Wilson, 1966, p. 17, 18). Because healing implies wholeness, for a person to be truly healed, attention must be paid to a person’s spiritual and religious needs. A very important tool in the patient's spiritual armoury can be their stubbornness, sheer bloody mindedness and refusal to give up.

3 Surviving

How are people enabled to survive periods of darkness in their lives? Bonhoeffer, for example, approached his enforced imprisonment by treating it as an extended sabbatical, “a good spiritual Turkish bath” (Bonhoeffer, 1971, p. 22); as an opportunity for study in an attempt to normalise the abnormal; and so he craved books and intellectual conversation. He was

also buoyed up by glimpses of the outside world: sunlight, the stars, a bird singing, a church bell ringing. Furthermore, despite being denied the sacraments of the church and the physical fellowship of other Christians, the church's year, especially its feast days, also gave a structure to his imprisonment, certain periods seeming more poignant than others. Aspects of the church's liturgy were also important, reading the Bible which he attempted to do “straight through from cover to cover” (the book of Job carrying a special resonance), and the singing of psalms and hymns (Bonhoeffer, 1971, p. 40). Then there were the reflections that flowed from this. Another way that Bonheoffer strove to keep a positive frame of mind was by pleading the justness of his cause such as in his letters to the Judge Advocate (Bonhoeffer, 1971, p. 64 - 69). For Bonhoeffer, it was also important to receive news of his family and friends. April 25th 1943 was Easter Day, it was also his fiancée’s birthday. He imagines conversations with them, their well-being or otherwise, concerts they have been to which he has imagined attending in his mind, sometimes confirmed in future correspondence and rare visits. For Bonhoeffer, “the great thing is to stick to what one still has and can do …. and not to be dominated by the thought of what one cannot do, and by the feelings of resentment and discontent” (Bonhoeffer, 1971, p. 38 -39).

Patients may use similar strategies to cope with their “incarceration” by finding something that gives a structure to this experience. Whatever is chosen is something that gives the patient a sense of being rooted in some

way that speaks of what it means to exist other than in a hospital setting, in short, retaining a sense of hope. For the Christian, the church's liturgy, with its calendar, sacraments, cycle of prayer and Bible reading, can be of inestimable value. For others it can be even using enforced hospitalisation as an extended sabbatical. Bonhoeffer's preclusion from being able to attend services or receive the sacraments and the detrimental effect it had upon him, serves as a useful reminder to any who fail to register the importance of attending to patients' religious and spiritual care needs.

Frankl, in wondering how prisoners, including himself, survived their incarceration, observed that they seemed to pass through three stages in an attempt to process their experience from initial imprisonment to liberation (for those who were liberated). These were: “shock”; “apathy”; “and … sheer ‘disbelief’” following his release and liberation” (Frankl, 1946, p. 6ff). Unsurprisingly, he spent most of his time looking at the second stage, the stage we might describe as that of institutionalisation. There seems to have been a conscious decision on behalf of some prison guards to break prisoners' wills sometimes overtly, by beating them into submission and more covertly by depriving prisoners of the best of the paltry food rations, and in the way they treated the sick and the dying as perfectly expendable commodities. As a fellow prisoner, Frankl comments, “All we possessed was our naked existence” and the ability to “choose one’s attributes in a given set of circumstances, to choose one's own way” (Frankl, 1946, p. 13, 65). Understandably, saving your own skin was foremost in a prisoner's survival

toolkit. This was made all the easier by a complete “lack of sentiment” both to one another and to the outside world. Frankl observes that there was no talk of cultural matters other than politics or religion (Frankl, 1946, p. 32, 33). It is as though awareness of the higher human qualities would underline the depravity of prisoners’ day to day existence.

And yet, talk of religion, “was the most sincere imaginable...The depth and vigour of religious belief often surprised and moved a new arrival. Most impressive in this connection were improvised prayers or services in the corner of a hut, or in the locked cattle truck in which we were brought back from a distant work site....In spite of all the enforced physical and mental primitiveness of the life in a concentration camp, it was possible for spiritual life to deepen.” It is as though people who suffered outwardly “were able to retreat from their terrible surroundings to a life of inner riches and spiritual freedom” (Fankl, 1946, p. 33, 35). Related to this religiously spiritual world was the calling into one’s mind one's loved ones. Whether they are physically present or not “ceases somehow to be of importance”. For Frankl, “love is the ultimate and the highest goal to which man can aspire...*The salvation of man is through love and in love* (author’s italics) (Frankl, 1946, p. 36, 37).

Frankl talks of the importance of developing a sense of humour which he sees as “some kind of trick learned whilst masking the art of living” (Frankl, 1946, p. 43). He gives the example of the more privileged prisoners from

time to time improvising “a kind of cabaret” which was so valued “that a few ordinary prisoners went to see the cabaret in spite of their fatigue even though they missed their daily portion for food by going”. At the end of the day, humour was another of the soul's weapons in the fight for self-preservation – “sometimes quite literally it could save your life if you clapped those prisoners who were the guards' informants” (Frankl, 1946, p. 43). Frankl tells of camp life having to be lived in the present, in the immediate 'now'. “Everything that was not connected with the immediate task of keeping oneself and one's closest friends alive lost its value” (Frankl, 1946, p 49). So, for example, prisoners would take the clothes of sick patients if these were better than their own. To keep oneself “safe” in Auschwitz, a prisoner “generally answered all questions truthfully but...was silent about anything that was not expressly asked for” (Frankl, 1946, p. 53). Not being noticed was key to surviving.

In hospital, institutionalisation can establish itself very quickly too. For patients, after the “shock” of admission, can come, if not “apathy”, the desire to “play the game”. After a long admission, there can be “disbelief” that the time has come to go home. For patients who have undergone particularly critical episodes there can be “disbelief” that they are still alive. But there will also occasionally be those patients who cut themselves off from other human contact and from the rest of the world, enduring their illness in self-imposed isolation.

Of particular relevance to those patients suffering from life limiting illness is the importance of life having to be lived in the present, as one of the by-products that such a diagnosis can instill is a reassessment of their perception of time. Whilst dwelling in the past is still possible, making plans for the distant future is not. And preoccupation with the past is frowned upon if it is seen as wasting time. Living fully in the present (or more fully than before receiving their diagnosis) also serves to bring greater intensity to the inner life of the patient. A sense of hope is paramount. Not false hope that has no basis in reality, but hope in that which can be achieved.

Thus, not just passively coping with, but actively surviving a difficult experience, is achieved through sensing order in the midst of chaos and by contextualizing it within a larger frame of reference. If pain allows, this enables a patient to enter more deeply into the immediately lived present. Furthermore, the ability to love and know that one is loved, and the ability to hope, can be experienced as the immanent and transcendent presence of God. This remains true, even if the patient's illness results in their death, as it can allow them to actively prepare for it, something that requires great honesty and courage.

4 Human courage

Before one can ask, as Bonhoeffer does, "From whence comes a person's ability or inability to courageously stand up to evil?" (Bonhoeffer, 1971, p. 4),

one needs to address the far more basic question “From whence comes a person's ability or inability courageously simply to be?” For Tillich, this is inextricably bound up with the existence of God, as he regards God as the source or ground of our being. When confronted with nothingness and annihilation, humankind needs in some way to affirm a sense of being. This is done by affirming that God is the source of all being which, in turn, stimulates in humankind the courage to be, which is the antidote to existential anxiety.

Tillich describes this courage in the following way. It is “the self-affirmation of being in spite of the fact of non-being. It is the act of the individual self in taking non-being upon itself by affirming itself either as part of an embracing whole or its individual selfhood”. For Tillich, “courage always involves a risk, it is always threatened by non being, whether the risk is of losing oneself and becoming a thing within the whole of things or of losing one’s world in an empty self – relatedness” (Tillich, 1952, p. 147). The courage of which Tillich speaks, “needs the power of being, a power transcending the non being” which he describes in the following ways. This power, paradoxically, “is experienced in the anxiety of faith and death...is present in the anxiety of emptiness and meaninglessness...is effective in the anxiety of guilt and condemnation.” This courage, as well an incorporating “ the power of being... transcending the non being” also “must be rooted in a power of being that is greater than the power of oneself and the power of one's world”(i.e. God).

Tillich believes that because of this, “this means that every courage to be has openly or covertly a religious root” (Tillich, 1952, p. 147 - 148).

Influenced by Jungel, Lewis extends Tillich’s thinking by concentrating not on ‘being’ but the process that takes one from ‘being’ to ‘non-being’ and vice versa (Jungel, 1983 p.368 cited in Lewis, 2003, p. 255). Writing out of a theology of Holy Saturday (which “provides a unique boundary point from which to consider interconnections between themes of Good Friday and Easter”), Lewis sees that which is threatened by proceeding towards ‘non-being’ as equally open to the possibility of proceeding towards ‘being’ (Lewis, 2003, p. xi). He believes that “for what is perishable and mutable, it *is* possible to change and become new…the perishable…that which struggles between being and non-being, richer, fuller more pregnant with potential than being itself” (author’s italics) (Lewis, 2003, p.246).

Returning to Bonhoeffer's initial question, the ever present dangers that might prevent evil being challenged he sees as occurring when a person is being reasonable, or doing their duty or being privately virtuous, each of which can provide an excuse for not engaging with the other at all. As Volf makes clear, writing out of the Balkan situation, ethnic cleansing also refuses to create a “space to receive the other.” Indeed, it takes the view that “ethnic otherness is filth that must be washed away from the ethnic body.....The result: a world without the other” (Volf, 1996, p. 57). Whilst the

former could be regarded as a sin of omission and the latter one of commission, the ethical positions are strikingly similar. Sadly, unjust structures that marginalise the vulnerable are just as capable as existing in hospitals as anywhere else.

Within healthcare, questions for the chaplain to bear in mind in encounters with patients might be: What gives them a reason to live? What gives them the courage to be, to embrace the otherness of God? It may be the love of family and friends, or the desire to get as much out of living as they possibly can, or to pursue a particular task, or to complete a project, or to serve humankind or to serve God. For those who want proof that God exists, Tillich's view that there are no valid arguments for the “existence” of God, can be liberating for the chaplain if appearing apparently unhelpful to the patient (Tillich, 1952, p. 172).

5 The nature of God

Reflection on life's dark experiences such as suffering, sin and evil and humanity’s courageous capacity for surviving them, cannot help but raise questions concerning belief in, and the nature of, the Godhead. Matthew, in his commentary on St. John of the Cross, states, “It is not God's absence, but the way he is present, that may cause us difficulty” (Matthew, 1995, p. 76). For Ford, the discerning of God's presence or absence is bound up with rediscovering a theology of wisdom (Ford, 2007, p. 3). For Moltmann again

the crucial question is “How one can believe in God at all in the midst of so much suffering?” Hick asks this question slightly differently “How there can be any belief in a God of love when evil so clearly is intricately bound up with the world in which we live?” For Moltmann, the question is directly related to the horrors of Auschwitz. which leads him back to realising that this must be related to how one can believe in God after “the profane horror and godlessness” of the Cross (Moltmann, 1974, p. 28). For Garrison, just as God can be sensed in the midst of crucifixion, “so too must we be willing to perceive God in the atom bomb” (Garrison, 1982, p.5). For both, the link with the crucifixion is essential as over the passage of time, the true awfulness of the cross has lost its biting edge. In his preface to “The Crucified God”, Richard Bauckham says “Moltmann has always believed that the Christian theologian can speak relevantly to the contemporary world only by confronting and understanding as adequately as possible the basis of the Christian faith in the life, death and resurrection of Jesus Christ.” (Bauckham cited in Moltmann, 1974, p. x) Young would concur as for her, in the midst of the difficult moments of caring for her son, “the only thing that makes it possible to believe in God at all is the cross” (Young, 1990, p. 75).

What does Jesus's cry, 'My God, my God, why have you forsaken me,' actually mean? “Who is God in the cross of Christ who is abandoned by God?” (Bauckham cited in Moltmann, 1974, p. xviii) But this abandonment is a bridge that reaches out to others who have felt abandoned by God. Bauckham describes it thus “Those with whom the crucified Jesus is

identified in his abandoned death are both *the godless*, who experience their own turning from God as God's abandonment of them, and *the godforsaken* who experience their suffering as God's abandonment of them" (my italics) (Bauckham cited in Moltmann, 1974, p. xi). So Moltmann, in contemplating the cross, is drawn to explore the very identity of God which he sees not in God as a person projected in heaven (with the implicit problem of impassibility inherent within this position), but in a Trinitarian perspective, rooted in divine love. "The Father who abandons him (the Son) and delivers him up suffers the death of the Son in the infinite grief of love" (Moltmann, 1974, p. 251). Whereas Jesus is identified with the godless and god-forsaken, God is regarded as our fellow sufferer.

Moltmann found that he needed to reclaim Trinitarian theology from some of its historical aberrations (Moltmann, 1974, p. 244). Young, writing sixteen years later, is still advocating "regaining a sense of seriousness about the mystery of the Trinity" (Young, 1990, p.246). But Moltmann states, "As Schleiermacher rightly said, any new version of the doctrine of the Trinity must be a transformation which goes right back to its first beginnings" (Moltmann, 1974, p. 248). This is what Moltmann seeks to do.

In the context of her own work, Soskice sees this transformation in terms of a doctrine which "promote(s) male hierarchy" returning to its roots which were "to subvert hierarchical readings" (Soskice, 2007, p. 110-111). Whilst

acknowledging that of its time, “the hierarchical expectations of fatherhood and sonship were up-ended by the formulations of the doctrine of the Trinity”, rather than focusing on the gendered imagery of father and son, she prefers to concentrate on the imagery of “kinship” (Soskice. 2007, p.5). Understood in relational terms in which relationships begin and end, just as “the advent of the child gives birth to the father” so too ”the death of the Son is in some sense also the ‘death‘ of the Father who is one with the Son” (Soskice. 2007, p.117). As the Spirit is expired at the death of the Son (and the Father), so it inspires the church. Soskice maintains that as “all three persons figuratively give birth (as well as die)… the activity of all three can be styled in the procreative imagery of the human feminine and the human masculine” (Soskice. 2007, p.118).

As Bauckham has suggested, for Moltmann, the doctrine of the Trinity “means primarily that there is inter-subjective relationship within God” (Bauckham cited in Moltmann, 1974, p. xii). It is a paradigm for perfect loving, perfect relationality. “It is *unconditional* and therefore *boundless* love which proceeds from the grief of the Father and the dying of the Son and reaches forsaken men in order to create in them the possibility and the force of new life” through the Spirit (my italics) (Moltmann, 1974, p. 253). In this, Moltmann builds on Tillich's view, not only that the doctrine of the Trinity provides a dynamic model of “the inner life of God”; but also that, because an immediate link is made between the being of humanity on earth and the being of the ground of all being, God, the microcosm is seen to be seeking to

emulate the macrocosm (Tillich, 1952, p. 170). We too “are relational beings” (Soskice. 2007, p.121).

Rather than seeing this perfect loving of God taking place within history, Moltmann locates history itself within the embrace of God. For, he believes, “To think of 'God in history' always leads to theism and atheism. To think of 'history in God' leads beyond that into new creation....To think of 'history in God' however, first means to understand humanity in the suffering and dying of Christ, and that means all humanity, with its dilemmas and its despairs.” (Moltmann, 1974, p. 255) And this has implications for how Moltmann understands God. Matthew's description of the God John discerns in the Dark Night of the Soul are equally applicable here: “God is greater than our feeling of God, our concept of God..... a God who is greater that we are, has room to impinge,” and to do so in a transformative way (Matthew, 1995, p. 85).

Moltmann regards God as “an event”, the event being “the event of Golgotha” (Moltmann, 1974, p. 255). So for Moltmann, “There is in fact no ‘personal God’ as a person projected in heaven. But there are persons in God: the Son, the Father and the Spirit. In that case, one does not simply pray to God as a heavenly ‘Thou’, but prays *in* God. One does not simply pray to an event but *in* this event.” (author’s italics) (Moltmann, 1974, p. 255) For Moltmann, what is important is the existence of “love as an event in a

loveless, legalistic world" in which love gives to the unloved "a new identity (which) liberates them from the norms of social identifications and from the guardians of social norms and idolatrous images" (Moltmann, 1974, p. 256). Love, imaged to perfection in the doctrine of the Trinity, is ultimately "an eschatological process open for men on earth which stems from the cross of Christ" (Moltmann, 1974, p. 256).

Moltmann's thinking has much to offer patients who are struggling to either retain or rediscover or perhaps discover for the first time where God might be for them in the "dark places" of human experience, whether those "dark places" be born out of mental anguish or physical suffering. Moltmann makes clear that "The Christian theologian (and therefore also presumably the Christian chaplain) can speak relevantly to the contemporary world only by *confronting* and *understanding as adequately as possible* the basis of *the Christian faith* in the *life, death and resurrection of Jesus Christ.*" (author's italics) (Bauckham cited in Moltmann, 1974, p. x) In order that *confronting* may have a chance of leading to *understanding, engagement* with the patient's pastoral situation in the light of the teachings of the church, including scripture (and vice versa), is essential. But this engagement will bear very little fruit unless there is a shared understanding of the terminology that is employed. A way of helping the patient towards a Trinitarian perspective of God rooted in divine love might be to adopt McFague's suggestion of using "the relationships nearest and dearest to us (providing, that is, they are affirming relationships) as metaphors of that which cannot

be named" (McFague,1982, p. 194). Either way, there can develop a sense of the patient being held within God's loving embrace. Having a sense of the presence of God offers a framework in which meaning can be discerned.

6 That which gives life meaning

As has already been stated, in order to discover afresh "Emanuel 'God with us'" and thereby discover a renewed sense of meaning to our lives, "what is required is a new conceptualization of both humanity and divinity" (Garrison, 1982, p.3). In terms of speaking about God, (and one might add, in speaking about one another and our relationship with God) McFague maintains that this language is provisionally relational (McFague, 1982, p. 194). Such relational language, whilst saying something "not only about God but about us, reawakens us to the promise of what we may become" (Soskice, 2007, p. 2, 3). The use of metaphor and symbol as a way of extending this relational language is developed in Chapter 3 (p. 128 - 132). The development of a Meaning-Making Cycle is explored in Chapter 5 (p. 155 ff). Understanding both humanity and God in this relational way, and seeking humanity within God, and God within humanity Ford terms as wisdom. As an example of the former, he explores the book of Job and whether it has any light to throw upon the Holocaust; as an example of the latter, Jean Vanier's L'Arche communities. Where humanity within God and God within humanity is not apparent, Ford finds that a feature to be found both in scripture and contemporary life is that of the cry from the heart, that cry of frustration indicating that meaning cannot be sensed. He sees a link between cries

“that arise from the intensities of life” and wisdom; for what are “cries” other than a demand for “theological wisdom”, for understanding amidst that chaos of living (Ford, 2007, p. 5). Finding faith within the chaos of living can be challenging, and it is just as challenging within the healthcare setting as elsewhere. Speaking out of her own situation Young acknowledges, “There was that desperate cry of the heart but there was no faith that said a prayer could be answered.” (Young, 1990, p. 63) For Ford, these cries are to be set within the context of “loving God for God's sake”. In his view, the key text out of which the book of Job emerges and to which it returns, is that Job's wisdom is rooted in “the fear of the Lord” (Job 28: 28 [RSV]).

For those who can only sense the absence of God, perhaps “loving for loving’s sake” in the midst of an experience of “fear” is all that one can hope for, the love of God modelled by the love of family and the loving care of healthcare staff. It is about process, a stepping forward in faith (in God, family or friends), about being questioning and searching but also “about being questioned and searched” (Ford, 2007, p. 93). Unlike the 'wisdom' of his friends, for Job wisdom it is not born out of “(pre) packaged answers”. It is a journeying along the way of meaningfulness, where God’s presence can be sensed (Ford, 2007, p. 93).

In one sense, Job is about a suffering individual. Indeed Garrison would see this as “an internal conflict” in which Job “feels free to call upon God for an

advocate against God" (Garrison, 1982, p.168). But Ford points out, "it is also about this individual in passionate engagement with his community of friends and with the God of community and its traditions" (Ford, 2007, p. 122). Indeed the friends come to epitomise this tradition. Ford believes that Job is relevant to communities that are suffering. He believes "there can be no neat formula for dealing with trauma; a wise response is likely to encourage each person and community to learn from the past while trying to do full justice to their own specific experience" (Ford, 2007, p. 123). And the tradition must listen to the authentic response expressed in the here and now, be "open to new possibilities and surprises, even in the sphere of … core convictions" (Ford, 2007, p. 129). If it fails to do this, as with Job's friends, the tradition can be perceived as attacking the current community experience.

Importantly for Ford, Job's sense of God is not dependent on whether he perceives God to be absent or present. Young would agree (see Young, 1990, p.81). For Job, God's existence is not in doubt, or, as Young puts it, "What satisfies… Job is simply the reality and (therefore the) presence of God" (Young, 1990, p. 91). Whereas Job's friends "see God's transcendence as one of indifference, Job does not take this position himself" (Ford, 2007, p. 130). And for Job, "addressing God takes precedence over speaking about him" (Ford, 2007, p. 131). Ford believes that Job cries out to God, not in order to get his old life back but "in order to get God back" (Ford, 2007, p. 132). Maybe this is what some patients seek

to do also when they vent their anger against the God who appears to be absent. In Young's view, "What God says is irrelevant", if indeed he is perceived as saying anything at all (Young, 1990, p. 91). And retrieving a sense of God can only be by engaging in the struggle that draws him "simultaneously into wrestling with the realities of history, including its trauma, and with God and God's purposes" (Ford, 2007, p. 135).

Turning to the L'Arche communities and the relationship between the able bodied and disabled, Ford believes it to be "an example of corporate wisdom-seeking" in which God can be sensed as being present within humanity (Ford 2007 p. 356). In these communities, Ford records the perception "that each person's life is of infinite value; that there is a mysterious blessing in weakness and poverty and that God is close to the broken hearted" (Kearney, 2000, p. 18 cited in Ford, 200,7 p. 351). Central to L'Arche is listening to one another's stories and discerning God's presence within them in interpreting them "in relation to sacred stories, above all Jesus". "Each person cries in his or her own voice and each responds in his or her own way." (Ford, 2007, p. 357)

Recalling Matthew's words concerning St John of the Cross (mentioned above) that "If God is beyond us, his approach is also liable to leave us feeling out of our depth" (Matthew, 1995, p. 56); Ford is clear that the trauma of profound learning disability does not have the last word because "the very

extremity of involvement elicits from each cries that can become a measure of the mystery of God who remains the God of blessing" (Ford, 2007, p. 365). In quoting Vanier, "true growth comes from God when we cry to him from the depths of the abyss to let his Spirit penetrate us" (Vanier, 1989, p. 133 cited in Ford, 2007, p. 367), Ford believes that L'Arche proclaims that "God desires a relationship with us for our own sake and for this to be reciprocal" (Ford, 2007, p. 369).

Ford's discerning of the L'Arche communities as "an example of corporate wisdom seeking" resonates particularly with those working with patients with life limiting illnesses, most especially within the hospice setting (Ford, 2007, p. 356). Such an illness focuses one's attention not on the quantity of one's life but on its quality, the importance of living life in the here and now without wasting a single moment. The fact that some terminally ill patients have a tranquillity about them which often eludes their relatives, speaks very forcibly of the "mysterious blessing in weakness" of which Ford, quoting Kearney, speaks of those with learning disability (Kearney, 2000, p. 18 cited in Ford 2007, p. 351). L'Arche communities and hospices are beacons to the fact that "those who have already been consumed by love can never be annihilated" (Davis, 2000, p 297 cited in Ford, 2007, p. 388). For those who give and receive it, love bestows meaningfulness. It is its own justification.

Conclusion

At the heart of this chapter has been the question, "Where and how is God discerned in the 'dark places' of human experience?" together with its subsidiary, "How can we believe in a God who allows suffering, so much of which seems so random in nature?" Experiences born of darkness, suffering, sin and evil, surviving, human courage, the nature of God and that which gives life meaning, were collaged with examples of received tradition by way of generating an authentic discernment of the presence of God. As with Cassidy (who posed the original question), it is suggested that the only way that God can be believed in with any credibility, is if God can be seen to be involved with, and supportive of, humanity in the midst of its suffering. That involvement and support may itself be discerned in the wisdom born of personal suffering through which the unique voice of the sufferer is articulated in a form of lament, a theme often found in the Psalms and one to which I shall return when exploring the "metaphorical language" of music (McFague, 1982, p. 25-26). The lament may itself give voice to a sense of the presence of God, if not in the earthquake, through the still small voice.

Chapter 2

God in the darkness - Clinical Literature Review

Introduction

The previous chapter concluded with maintaining that the only way that God can be believed in with any credibility is if God can be seen to be involved with, and supportive of, humanity in the midst of its suffering. This chapter continues the process of engaging in "critical dialogue between theological norms and contemporary experience" (Pattison and Lynch, 2005, p.410 - 411), and explores whether this position can be supported by examples taken from a clinical perspective. An approach will be employed in which relevant literature concerned with "dark places" of human experience within the healthcare setting will be considered in the light of relevant case studies drawn from my own praxis. The areas I shall explore will include: end of life care; bereavement; loss; disability and dementia.

1 Being diagnosed with a life limiting illness.

The obvious "dark experience" within the context of health care in which one comes face to face with the reality of loss in all its starkness, is when a patient is diagnosed with a life-limiting illness in which, maybe for the very first time, they begin to realise that life itself is a terminal condition. Most patients in hospital look forward to a time of full or partial recovery. A patient

with a life limiting illness has to try to begin to make sense of a world view in which this will not be true for them. They may be helped through various crises, but their underlying prognosis will not improve and will eventually deteriorate. Kubler-Ross has sought to describe the process that a patient undergoes in seeking to adjust to this new dispensation. Whilst clearly not everybody reacts to a difficult diagnosis in the same way, she discerned four key stages through which people pass. These are: denial; bargaining; depression and acceptance. Although in describing them, the appearance can be given of a linear journey travelling in one direction, Kubler-Ross herself points out that this is usually not the case (Kubler-Ross, 1970). People can become stuck, go backwards, have several attempts at a stage, almost needing to build up a physical momentum in order to move on to the next stage.

When a patient first becomes aware that they have a life-limiting illness, the shock can cause them to go into *denial (1).* Kubler-Ross believes this to be no bad thing as she believes that “the need for denial exists in every patient”, giving space for the information to be digested and in time, absorbed (Kubler-Ross, 1970, p. 37). But during this information digestion process, the patient may vent their frustration on anybody close at hand, even on themselves. Kubler-Ross observes that “grief, shame and guilt are not very far from feelings of anger and rage” (Kubler-Ross, 1970, p. 4). But if no overt anger is expressed there can be a real worry that the person has not yet faced up to their own mortality.

And then the *bargaining (2)* begins as the patient can fall back on notions of reward and punishment so prevalent in childhood. The patient believes that "there is a slim chance that he (she) may be rewarded for good behaviour and be granted a wish for special services. His (her) wish is most always an extension of life, followed by the wish for a few days without pain" (Kubler-Ross, 1970, p. 73). When the bargaining doesn't work, and the stark reality of the patient's situation becomes overtly apparent, a factor which can render a person physically, mentally and spiritually exhausted, a patient can become extremely *depressed (3),* both in response to the bad news itself and the loss that their death will presage. But Kubler-Ross believes that "If a patient has had enough time...and has been given some help in working through the previously described stages, he (she) will reach a stage during which he (she) is neither depressed nor angry about his (her) fate." (Kubler-Ross, 1970, p. 99) And only then can the final stage of *acceptance (4)* be deemed to have been reached (with the proviso that people can still regress to earlier stages).

Case Study 1.

"T" was a middle aged male Motor Neurone Disease (MND) patient who came onto the ward at the local hospice. He had been an extremely active man, serving as a police officer, and had done a lot of football coaching with youngsters. He felt very deeply the unfairness of this illness which he

described as living hell. Since his diagnosis, the patient had thrown himself into fundraising for the MND association. These fundraising activities culminated in him being sponsored to walk the Normandy beaches with his best friends which was videoed for posterity.

When he began what turned out to be his final stay at the hospice (which lasted a number of weeks), his room (which is specially designed with MND patients in mind) had his name on the door. It became an extension of his own home with family and friends coming and going most of the time. His personality dominated the room. It became a place where staff dropped in to be cheered up. He insisted on being the person that he had always been, who just happened to be ill. Having checked with the staff first, friends would “kidnap” him and take him off to football matches or to the pub where he could have a drink with his friends. They continued to drop by, even when he became too ill to leave the hospice.

Throughout his life, “T” had faced difficult situations head on. With the chaplains, he became keen to write his own funeral eulogy. He wanted to complete this not just before he died, but before he could no longer talk. This was honed over many weeks. As I was the chaplain on duty when he died, the family asked if I would deliver this eulogy at his funeral. Despite some rather 'rich' language, it was read word for word as he had intended.

What is vital for the patient in this whole process is the keeping hope alive, which is achieved through the quality of the interaction of the carer with the patient which, whether articulated or not, is one way in which that patient can sense the presence of God. If a patient is not loved, or if their loved ones have given up on them, the very real impression is given to the patient that "slowly but surely he (she) is beginning to be treated like a thing" (Kubler-Ross, 1970, p. 99). Socially they will feel that they have already died.

2 Grieving the loss of a loved one

A direct parallel to trying to come to terms with being diagnosed with a life-limiting illness is the "dark experience" of knowing that a loved one will die or has recently died. Parks and Weiss have observed that people seem to respond differently to bereavement. "Some recover from grief unscathed, or even strengthened, while others suffer lasting damage to body, mind or spirit" (Parkes and Weiss, 1983, p. ix). Key to how a person grieves is the importance "of the value of preparation in dealing with inescapable pain and loss" which, as we shall see below, is also acknowledged by Speck. As Kubler-Ross observed with terminally ill patients, people need time to adjust to their newly bereaved (or soon to be bereaved) condition. "They must first be given support and time to grieve for the loss of the cherished past." (Parkes and Weiss, 1983, p. 255)

When a person grieves, whether it represents “a struggle between opposing impulses, one tending towards realisation of the loss, the other towards retention of the object”, or it represents a constant looking for the one that is lost, Parkes and Weiss are clear that grief is normative at the death of a loved one, it is the “absence of grief” that is not (Parkes and Weiss, 1983, p 2). Elsewhere Parkes has written that “grief is a process”. Mirroring Kubler-Ross’s grief stages of denial, bargaining, depression and acceptance, he identifies the phases of grief as “numbness...pining...disorganisation and despair...recovery”. Like her, he recognised that people “can move back and forth through the phases” (Parkes, 1996, p. 7).

Some people clearly find it hard to begin the grieving process. This Parkes and Weiss refer to as 'pathological grief'. This can be observed when there has been: “sudden unexpected bereavement, a reaction of anger and/or self-reproach (ambivalence) against the deceased,....intense yearning, often associated with a supposedly dependent relationship” (Parkes and Weiss, 1983, p. 52). That which is important in having a bearing on when grieving can begin is “the mode of death,...the types of social support that are available... (and) the predisposition of the bereaved (e.g. their age)” (Parkes and Weiss, 1983, p. 17 – 18). That which has a bearing on when grieving can draw to its close is “the nature of the relationship with the person who has died, the personality of the survivor...(and) the surrounding social circumstances” (Parkes and Weiss, 1983, p. 19 – 20). Yet others can be so well prepared before their loved one's death, they want them to get on and

die! As Parkes and Weiss warn us, “It is sometimes tempting for us to want to put patients out of *our* misery” (authors’ italics) (Parkes and Weiss, 1983, p. 256). But the greatest amount of preparation can't eliminate totally the trauma felt by the loss of a loved one when they have actually died.

Case Study 2.

“C” was an eight year old girl who died on the Children's Ward nine months after I became chaplain at my present hospital. She had been diagnosed with a type of bone cancer some months before and was well known to the community paediatric team. During the course of her illness one of her legs had been amputated in an attempt to stop her cancer from spreading. Having been stabilised by medication that enabled her to travel to Disneyland in Florida so that she could “swim with the dolphins”, her final healthcare crisis began there, involving her being intubated and flown back to the UK and, at the parents request, being transferred to the Island. As I was with her parents and “C” when she died, I was asked to take her funeral. When I undertook the pre-funeral visit at the family home, it became clear that “C”s father was very bitter at his daughter's death. He placed “C”'s prosthetic leg on my lap and was insistent on showing me “C”’s hair which the parents had kept from when she lost it through her chemotherapy.

She was one of four children diagnosed with cancer on the Island in a very short space of time. Because they became friends, so too did their parents.

One child had died before “C”, one died shortly afterwards and one is still alive. These last two children attended “C”s funeral. The four families remained very angry at the diagnosis of the children’s cancers. They were convinced there must be a common cause. When this was not found to be the case, the parents' anger increased. They began to look for a scapegoat. Some of their anger was turned towards some members of staff on the children’s ward which resulted in one member of staff going off sick and subsequently leaving. A clinical psychologist was brought in by the hospital to help this group of parents work through their grief. He involved me to see if there might be a way in which this grief could be worked through symbolically in worship. This led to the setting up of the first children's memorial service, with these bereaved parents becoming the planning group for this event. In subsequent years, as the parents anger dissipated, this group also included members of staff. At the time of writing, we have just marked this service's 12th anniversary. It takes place not in the hospital chapel but by the hospital lake. The central point of this service is the reading out of the names of children who have died followed by the release of multi-coloured balloons and the blowing of bubbles. “C”'s family have attended most of these services.

The grief that “C”'s family members felt at the death of their child was the last of a number of losses they have had to see her endure (and because of their love for her, endure themselves). A question which has remained unanswered is whether the establishment of the annual children’s memorial

services has helped or hindered the grieving process for “C”’s family and the families of her three friends. Is there a danger that every year as the same wounds of grief are reopened, the families are doomed to go round and round in circles? But because these services are rooted in a world faith (in this case the Christian faith), there is a sense in which those who are grieving are held in loving relationship with others who are grieving and with the source of life in all its fullness (whether overtly acknowledged as God or not) wherein lies the possibility of transformation.

3 Loss in other areas of health care

Bereavement is not the only form of loss, whether it is expected or unexpected. Many events in life often involve loss, as loss is a concomitant of change. “Arriving, departing, growing, declining, achieving, failing – every change involves a loss and a gain. Resistance to change...is the basis of grief.” (Parkes, 1996, p. 11) Parkes and Weiss are of the opinion that “the process of recovery from bereavement and the ways in which the process can be impeded may provide a model for recovering from any irremediable loss” (Parkes and Weiss, 1983, p. 254, 257 – 258). As with bereavement, what cannot be overstated is “the value of preparation in dealing with inescapable pain and loss” (Parkes and Weiss, 1983, p. 255). Speck has looked at specific losses that occur within health care.

Whilst Speck acknowledges the importance in preparing a patient for any predictable loss they are about to experience in health care, he believes that “One can never fully prepare someone for an experience not yet theirs.” (Speck, 1978, p. 18) Ideally, the preparation should not happen in isolation from the family as “a time of crisis for a patient can also become a crisis for those caring for them” (Speck, 1978, p. 24). But in practice, this is only likely to happen if the perceived loss to the patient is regarded as being significant to the clinical and nursing staff. Speck points out that there may also be problems if the planned loss does not occur, because, for example, an operation has been cancelled or a ward move has not materialised. Before any kind of health care procedure that may be causing the patient concern, Speck believes that “it helps if people can worry. But such worrying should be in relation to the worrying of the situation” (Speck, 1978, p. 19). For healthy worrying, as opposed to pathological worrying, is itself part of the preparation process. In relation to those preparing for surgical operations for example, Speck has noticed that those who worry most before an operation are “more likely to be full of anxiety afterwards”; those who are moderately worried beforehand are “less likely to show any external disturbance afterwards”; those who are most happy, who are “constantly cheerful” beforehand are often “not prepared for the indignities of post-operative care” (Speck, 1978, p. 20). Parkes and Weiss are of a similar opinion in their belief that “Being able to anticipate the limitations and potentialities of life after loss means that when the loss actually occurs, it makes a kind of sense, it is not out of the blue and adaptation need not combat the need to repudiate the reality of change.” (Parkes and Weiss, 1983, p. 255) Furthermore, Speck

maintains, that “being able to take an active part in their own recovery helped patients feel less helpless” (Speck, 1978, p. 20).

The very fact of coming into hospital is itself a loss, whether the admission is planned or unexpected. There can be a loss of freedom of movement and of action, one’s autonomy can be compromised, one can quickly become dependent on others for one’s most basic needs. With this environment of loss can come other losses. Speck has helpfully indicated what these might be. Within obstetrics and gynaecology these can include: “spontaneous abortion and miscarriage or still-birth… infertility...congenital abnormality... menopause.. hysterectomy” (Speck, 1978, p. 33 – 52). Within general surgery loss can include “mastectomy...colostomy... mutilation resulting from injury/surgery...amputation” (Speck, 1978, p. 53 - 76).

Speck stresses the importance for a patient to “be able to recognise his or her body image”, as disfigurement “can lead to stigmatisation”. Surgery can result for patients in a “loss of self-esteem” so it is vital that not only the staff but also the family and friends can give them a sense of affirmation. For “if the patient enjoys secure and loving relationships in which he or she knows that it is not physical appearance, ability or prowess that is the relationship, then he or she will be more able to resolve the feelings generated by the loss”. But one needs to bear in mind that “a loss may seem the same for

several patients but the significance of that loss will vary from person to person" (Speck, 1978, p. 76 – 77).

Then there is the sense of loss which is derived from a medical condition which Speck helpfully lists as including: "loss of vision...loss of hearing... Chronic Bronchitis...Asthma....Multiple Sclerosis....Epilepsy...Osteoarthritis... degenerative disc disease and Rheumatoid arthritis...cardiac failure....stroke (Speck, 1978, p. 81). Some of these conditions are related to the general ageing process which can of itself also be perceived as loss. These illnesses "often include the loss of independence, usefulness and purpose." For the younger patient, there may be "loss of employment" and a "change of status" - from able-bodied to "unemployable". As with post-surgical patients, "a positive and supportive approach to such patients with continuing encouragement, can lead to them adopting a reasonably active life style within the limits imposed by their illness" (Speck, 1978, p. 110).

Case Study 3

"S", an active woman in her sixties began her hospital stay in a six bedded bay on one of the orthopaedic wards. She came in for a standard knee replacement operation. Post-operatively she picked up an infection on her knee which was initially treated with drugs. Because of her infection she was moved to a single room on the same ward and was barrier nursed. Her physical and psychological condition deteriorated. Having thought she was

coming into hospital to have an operation that would help improve her walking, “S” now found herself bed bound and totally dependent on others. She had a strong Christian faith. It was important for her to receive Holy Communion weekly. This was brought to her by one of the hospital chaplains. As well as receiving the sacrament, this provided her with a regular opportunity to talk with a chaplain. It seemed to be important for “S” to be able to talk about how she was feeling to someone who was not a nurse or other clinical colleague for fear of taking up too much of their time; and someone who was not a member of her family for fear of upsetting them. Her conversation was full of questions: “Why me?” “What have I done to deserve this?” “Is God testing me?”

Because her leg was continuing to deteriorate, her clinical team took the decision that in order to save her life, they advised her to have a partial amputation. This was clearly on “S”'s mind when she next spoke to a chaplain. Whether it was that her sense of altered body image was such that if she could not remain complete, she did not wish to remain at all, or whether it was because she had such little power left to her that this was a way of externalising her frustration is not clear. The fact remains that “S” was adamant that she would not have the operation.

The family found this very hard to cope with and so over time felt duty bound to try and change her mind. Eventually, “S” acquiesced and agreed to the

operation. Her physical health improved, she was moved to the Rehabilitation Ward where she remained for many weeks. Being free from infection meant that she was able to attend the weekly Holy Communion service in the hospital chapel. “S” was measured for a new leg and found it very uncomfortable to wear. Indeed, on one occasion she had actually been given the wrong prosthetic leg! Describing to one of the chaplains how she found herself with literally two left feet was one of the few times she laughed during her entire hospital stay. When she was getting ready to leave the hospital, when asked by a chaplain how she was feeling now, “S” admitted very quietly that she had made the wrong decision about having the operation.

For “S”, her physical disfigurement was mirrored by a sense of spiritual disfigurement. Being denied adequate “worrying time”, she could not begin to process why God had allowed this to happen to her, but she never doubted that God existed. Despite being a member of a loving family, “S” seemed to find it impossible “to recognise her new body image” believing that she had been not just stigmatised but violated as a result of the operation (Speck, 1978, p. 76). Her spiritual situation remained unresolved when she left the hospital.

4 Disability

Disablement is another one of the “dark experiences” that one comes across in health care as well as in the wider community. Along with Jean Vanier, who we have already seen, was particularly interested in the relationship which is established between the disabled and able bodied when living together in community, two other key writers in this field have been Nancy L. Eiesland, a disabled person herself, and David A. Pailin, responding to the birth and short life of a severely disabled baby. Disablement, like beauty, would seem to be (to a greater or lesser extent) in the eye of the beholder, whether the “beholder” is the disabled person themselves or someone else. It would seem to have an objective reality bound up with clinical symptoms and a subjective reality bound up with how the disability is perceived and experienced by the disabled person and society in general, a perception which in no small way is shaped by the symbolism in common parlance accompanying disablement and able-bodied-ness. Pailin warns that one must always beware of “the error of judging other peoples' happiness and fulfillment in terms of what is appropriate for me” (Pailin, 1992, p. 9). Young makes a similar point when she says “Developing (a person’s) potential must not be confused with “normalization.”“ It must not be forgotten that “the handicapped person, like Christ, is made in the image of God” (Young, 1990, p. 190, 189). This can start to feel uncomfortable for those without marked disabilities, although people maybe dis-abled in non-physical and non-visible ways. Eisesland perceptively writes that meaningful symbols for those with disabilities must not only “change the way that people with disabilities conceive of our experiences and, in particular, our relationship to God, they

must also alter the regular practices, ideas and images of the able bodied" (Eiesland, 1994, p. 91).

Clearly the converse also holds true, in that unhelpful symbols for those with disability can increase their sense of isolation, even demonisation, as they find themselves propelled ever further into a ghetto of societal anti-matter. If there is a perception that the able-bodied have value, are whole, have self-respect and self-esteem; there will inevitably be the sense for the disabled person that they are of little or of no value, damaged goods, lacking in self-respect and self-esteem, imprisoned. Swinton's remarks concerning mental health patients are equally applicable here. He believes that it is matter of vital human dignity to find a way of "defining the person apart from their illness". For Swinton, "a key to such reframing of illness experience and the installation of hope lies in friendship" (Swinton, 2000, p. 137). Furthermore, to see a disabled or handicapped person "to be less than fully human... fails to recognise that all of us are limited;... that from the divine perspective, non-handicapped people are likely to be no more creatively significant than handicapped people" (Pailin, 1992, p. ix). After all, for the able bodied and disabled, alike, there is a "dependence of all life upon God" (Young, 1990, p. 61).

Even the very word "disabled" itself would seem to define a person negatively, in a way that , for example, the words "differently abled" don't do.

But would that be honest? That might be to give the impression that living with disablement (as Canon Scott Holland has said of death) “is nothing at all”. Clearly there are very real problems of fatigue for most disabled people engendered through their physical condition. As Eisesland recognises, “Living with a disability is difficult. Acknowledging the difficulty is not a defeat” (Eiesland, 1994, p. 13). Indeed ironically to do so may help take away the perception of being disabled. There is also a sense in which disablement can ameliorate suffering in those with learning disabilities for example. And for those who have “restricted powers of anticipation, what is not imagined will not be feared, what is not hoped for will not be missed” (Pailin, 1992, p. 40). Living with a person with a disability can also be difficult. In the context of caring for her disabled son Young says, “There has been no easy triumph, but the pain is shot through with joy and the joy is pierced with pain.” (Young, 1990, p. 61)

In the task of resymbolisation that Eiesland calls for, she believes that a way must be found in which able bodied and disabled people alike discover a common humanity in which we only find completeness by exploring ways of “holding our bodies together”, a term she refers to as “embodiment” (Eiesland, 1994, p. 95). And that requires a “coming to terms with our own bodies”. For the disabled person, this means being able to accept their bodies as “survivable” and as being “painstakingly honestly and lovingly constructed” (Eiesland, 1994, p. 96). The respect which comes from this acceptance is itself “an act of resistance and liberation”. But as with all

resymbolisation, this can be “both liberating for the marginalised group and unsettling for the dominant group” (Eiesland, 1994, p. 96). Pailin succinctly believes that able bodied and disabled people “should be judged by how far they have realised their potentials rather than their success in satisfying some attainment targets” (Pailin, 1992, p. 48-49). In other words, they should be driven by an internal rather than an external agenda.

One way that we can discover our common humanity is in the relationship that we have with God, born out of God's relationship with us. Lewis places this question firmly at the foot of the crucified Christ when hes asks, “What does it mean – globally, socially, individually – to be human…*Christian*… the *church…*(in the)… light of the cross? (author’s italics) (Lewis, 2001 p.101). Pailin puts it thus: “God cares for every person – in their pettiness and nastiness (which God wills to be transformed) as well as their love and creativity (which God desires to be enhanced).... God has the confidence to allow people to be themselves and to accept them for what they actually are”. We are for ever “embraced, cherished and valued by God”. The memory of each one of us is “everlastingly preserved in the divine memory” (Pailin, 1992, p. 52).

Although one might at first expect the health care environment to be broadly sympathetic to a disabled person, paternalism can still be experienced by them, made all the more invisible by its occurring in what one would

generally understand to be a healing and an affirming environment. Furthermore, their disability may itself be causing them problems by complicating their recovery, whether that is from illness, accident or surgery. It may be that their disablement has only begun with this hospital admission. It may be that their coming into hospital has given them their very first opportunity to talk with someone other than a family member about what it means to live as a disabled person. How a person relates to God as a suffering or disabled person is likely to be affected by whether or not these qualities are modelled within the person of the Godhead (see Moltmann in Chapter 1 p. 39 - 45 above).

Case Study 4

“R1” was a man with profound learning disability who lived for nearly twenty years in the residential accommodation run by my Trust for this client group. Despite being physically unwell for many months, when “R1” died in May 2010 aged 63, his death was sudden and unexpected. At the time of writing, whilst his mother is still alive, his father died last year and because he had no other relatives, the staff at his home became by default his extended family. With “R1”'s mother's permission it was they who arranged his funeral service. They asked me to take his funeral as they wanted someone that both they and “R1” knew.

When I went on the funeral visit to meet with staff, what became very clear was how upset people were, not just present staff but staff who were no longer working at the Trust but had worked closely with “R1” in the past. Despite “R1” needing semi constant care within the centre and when going on trips outside, his at times moody but often jovial nature, communicated to staff the person within as opposed to the disability without. This was particularly felt by staff who had taken “R1” on a holiday, sometimes with other clients, sometimes by himself. Because his father had worked in the RAF, “R1” was fascinated by planes and all kinds of transport. When he first met a person, as well as their name he wanted to know what car they drove. When staff went on holiday, they would always send him a card. which invariably had some means of transport upon it.

Because of the length of time “R1” had been a resident at the centre, for many staff his death has felt like an end of a chapter. Because of changes in the provision of care for those with profound as well as less severe learning disability, and the belief in my Trust that this care should be individually rather than communally targeted and provided by social service rather than health care, the death of its longest staying resident may, if not being the catalyst that enables this to happen, certainly come to symbolise the end of an era. Not only the staff but the other residents (some of whom attended “R1's” funeral), will feel this change very deeply.

It is impossible to conceive of “R1” separate from his learning disability. As far as he was able, “R1” seemed to live life to the full, helped in no small part by his dedicated carers. “R1's” world contained no artifice. When in his company, he demanded the whole of a carer's attention. But “R1” was not just a person who received care, he was quite cable of giving care too. Staff had a great loyalty towards him. Within the Christian world view, the staff could be said to be enfleshing the love of God by having the confidence to allow people (in their care) to be themselves and to accept them for what they actually are (Pailin, 1992, p. 52). Staff have found themselves transformed by this process, because they have allowed themselves to face the essence of what 'human being-ness' actually means. In short, “R1”'s vulnerability allowed staff to become vulnerable themselves as was born out by the grief felt at “R1’s” death.

5 Dementia

An initial reaction from those not suffering from dementia observing those who are, can be to see a de-compositional process at work, to witness a journey from order into chaos, an un-creation. Goldsmith is one of a number of writers to offer a different perspective, believing that it is in the “very essence of the Christian faith that we discern the presence and activity of God in brokenness and weakness. It is when we are at the limits of our powers and strength that we allow God to break through our defences and to support and sustain us” (Goldsmith, 1998, p. 8). So it is possible that those suffering from dementia have positive as well as negative insights to share

about the nature of what it means to be human, and to say something of God's relationship with his creation. Be that as it may, this in no way minimises the very real fear and anxiety that can be felt by the dementia sufferer and their loved ones as they watch on helplessly at the foot of their particular cross.

Bryden, a dementia sufferer herself, rather than perceiving dementia as a fragmentation or an annihilation of the self, sees it as a voyage of discovery. In quoting a fellow dementia sufferer's response to her condition, she writes, “I think the most releasing realisation I came to early in my journey with dementia was that the further I progressed with the physical/psychological decline the more my spirit man increased in proportion”. Bryden even feels that, as a result of her increasing dementia, “I am becoming who I really am” (Bryden, 2005, p. 161, 162). She draws on insights from Frankl as to how one might endure the trauma of dementia (see above Chapter 1 p. 31 - 33). “For people struggling with dementia, it is a similar path of survival, illusion, denial, apathy, humour and a search for meaning.” (Bryden, 2005, p. 162)

Drawing upon Israel's experience of exile in Babylon, Goldsmith suggests that just as the Children of Israel came to know God's presence in this unknown country, so too can the patient suffering from dementia. He believes that the opening verses of Psalm 137 are particularly helpful in making this point. “By the waters of Babylon we sat down and wept...How

shall we sing the Lord's song in a strange land?" (Psalm 137 v. 1, 4 quoted in Goldsmith, 2004, p. 13, 14). Goldsmith also talks of people "living in the 'space' between crucifixion and resurrection" (Goldsmith, 2004, p. 206). Following in the footsteps of St. John of the Cross, McDonald believes, that in regarding this space as Holy Saturday, the "'empty' day between the cross and the resurrection, where apparent defeat is not immediately followed by triumphant vindication, we are enabled, tentatively, to speak theologically of dementia....Holy Saturday shows us God in the emptiness and God taking the emptiness into himself" (McDonald, 2003, p. 6). What transforms this emptiness is God hanging on to us through his relationship with us. "It is the triune God who has taken into himself and overcome the rupture of Holy Saturday who upholds, and will transform, the apparently lost identity of those trapped in memory's tomb" (McDonald, 2003, p. 6). Lewis clothes Holy Saturday with the chilling phrase ""God incarnate and interred" (Lewis, 2001, p. 127). But these are not words of defeat but words that speak of the harrowing of hell, any hell.

One thing which is shared by, and unites, those suffering, and those not suffering with dementia is the recognition "that there is something within men and women which hints at or speaks of, that which is beyond them" (Goldsmith, 2004, p. 143). It is as though this is a gift that those with dementia give to the wider church. Everett applies this idea of passive gift to active challenge to much of western societal values when she says "People with dementia are magic mirrors where I have seen my human condition and

have repudiated the commonly held societal values of power and prestige that are unreal and shallow.....They....show us the masks behind which we hide our authentic personhood from the world." (Everett, 2000, cited in Goldsmith, 2004, p. 202) So in coming alongside those with dementia we can both feel their pain and become aware of our own vulnerability. This vulnerability can affect our theological thinking. If we are to honestly engage with those with dementia, our thinking must be rooted in "a theology of patience, of suffering and of 'failure'. We need an open-ended, non-judgmental and merciful theology, not a theology of certainty, but of tentative exploration" (Goldsmith, 2004, p. 204). For Goldsmith, as we saw earlier with Moltmann, this points back to the Cross which Goldsmith believes points to "the mystery of God and the nature of love" (Goldsmith, 2004, p. 205). Goldsmith firmly believes that "if we have no good news for the person with dementia, then surely we have very little good news to offer anyone else....nothing is required of us save that we be ourselves, And that is enough, that is always enough" (Goldsmith, 2004, p. 210).

Case Study 5

The Trust for which I work runs a centre which specifically cares for patients with dementia. Formerly it served as a respite function to which patients repeatedly returned and as a result of which significant relationships were established between staff, patients and their relatives. Now this unit functions as an assessment centre and this results in shorter and less frequent stays for patients. One tradition survives this change of function. Every year much

is made of the annual Christmas Carol Service and Christmas Party. One year, a male patient “R2” and his wife attended. He and his wife were sitting in the front row and so I couldn't fail to notice them when taking the Carol Service. “R2” had become very withdrawn and to all intents and purposes appeared to be asleep, until we sang the Carol “Away in a manger” when he began mouthing the words. When the carol ended, his word-mouthing ceased. I found myself profoundly moved by this experience.

In talking with “R2’s” wife after the service, it became clear she was very angry. This seemed to stem from the fact that because her husband was of West Indian origin and she was not, since their marriage at the end of the second world war she had faced years of racial discrimination. Life for her had become one long fight, her husband's dementia being the final unfairness that life had thrust upon her, fuelled by the loss of the respite function of the centre she had come to know and trust. She dealt with it as she always dealt with difficulties, by fighting. Despite being back at this centre, no care would ever be good enough for her husband. The staff at times found it very difficult to deal with her. A month after Christmas, “R2” died. I conducted his funeral. Apart from his wife, it was members of staff who formed the rest of the congregation, having become by default their extended family.

There seems to be a marked difference between how the unit staff regard their patient guests and how the managers of the service regard them. The first seem to be concerned about quality of life experience The second seem concerned about processing the maximum number of patients through the system. The annual Christmas Carol Service and Christmas Party can thus be regarded as counter cultural to, and undermining of, the assessment centre philosophy. It is as though remembering one story, the Christmas story, is allowing the re-membering of others, “the spirituality of religion” enabling “a search for meaning” to take place (Bryden, 2005, p. 162). “R2’s” mouthing of the words of the carol, , seemed to indicate that something of a spiritual as well as a physical awakening was taking place. It was as though “R2” was becoming re-acquainted with God's presence in this unknown country. In “R2’s” responding to the singing of the Lord's song in a foreign land, a moment of incarnation was taking place in our midst.

But this moment of revelation was framed by the anger of his wife, born out of one frustration after another, anger at his present deteriorating condition and anger at her inability to do anything to help. And yet, when “R2” died, his wife wanted his funeral to be a Christian service, perhaps a recognition “that there is something within men and women which hints at or speaks of, that which is beyond them,” “not a theology of certainty, but of tentative exploration”(Goldsmith, 2004, p. 143, 204).

6 Coping strategies

So how is it that we cope at all with these very difficult life experiences? What do we mean by “coping”? What do we mean by religion? What mechanisms do we employ? Pargament believes that “coping is, like religion, a search for significance. It is however, a search of a different kind” (Pargament, 1997, p. 89), and that learning more about the one will tell us more about the other (Pargament, 1997, p. 17). For those whose religion is central for their ability to cope, Pargament believes that “People cope religiously because religion is relatively available and accessible to them and because religion offers a more compelling route to significance than non-religious alternatives. The religious path is likely to be particularly compelling in boundary conditions where the limits of human resources come to the foreground.” (Pargament, 1997, p. 162)

Religion is not just “one thing” in coping. It takes on different forms at different times and in different places (Pargament, 1997, p. 196). The picture of God one can have in one's mind can change too (see p.17 - 19). Religion is not a fixed unchanging entity but in dialogue with its surroundings. So “the religion and coping connection cannot be understood through the person, the situation and the context alone. It is the interplay of these forces that determines when the paths of religion and coping will come together and when they will go their separate ways” (Pargament ,1997, p. 162).

In talking of the relationship between coping and religion, and of religion's ability to give (or not to give) an authentic context to the coping process, Pargament describes a kind of tidal process at work which adds to or takes away from a person's ability to cope in any given way. He says, “There is a pull as well as a push to coping and the pull comes from the character of significance. People generally choose ways to cope from the available options in an effort to maximise significance. But when viable options are not available, they create new ones or change the nature of the significance.” (Pargament, 1997, p. 197) One's religious faith either evolves or dies.

Pargament has evolved “a religious problem solving scale” which he expresses in the following way. Firstly there is “ the self-directing approach, wherein people rely on themselves in coping rather than God” [See above case studies 1, p. 51; 2, p. 55; 5, p. 72]. Then there is “the deferring approach, in which the responsibility for coping is passively deferred to God” [See above case study 3, p. 60]. Finally, there is “the collaborative approach, in which the individual and God are both active partners in coping” [See above case study 4, p. 67] (Pargament, 1997, p. 162). These approaches, whilst deductive must never become prescriptive. For example, one set of empirical studies has shown there to be a clear overlap between the collaborative and deferring approaches in cases of patients suffering from cancer (see Nairn and Merluzzi, 2003, p. 428 – 441).

Furthermore, Pargament is clear that coping strategies are not just about making sense of a present crisis in the light of previously held significances, but also about discovering new significances. This is really what Murray Parkes is seeking to address in his work on psychosocial transitions. He points out that psychosocial transitions "are not confined to bereavement, they take place whenever we are faced with the need to make changes to our assumptions about the world" (Parkes, 1996, p. 90). They also have a direct effect upon how we view ourselves. When a loved one dies, or is lost in some other way to us, not just one assumption but "a whole set of assumptions about the world that relied upon the other person for their validity are suddenly invalidated" (Parkes, 1996, p. 90). Parkes believes that what has to happen at such a time as this is that we "need to give up one set of habits (many of which may be so well established that they have become virtually automatic) in order to develop another" (Parkes, 1996, p. 90). Problems arise in this process of adaptation, Parkes believes, when what "is" gets out of step with what "should be" (Parkes, 1996, p. 91). Parkes identifies four possible changes of roles as being likely to take place. He lists these as follows:

1 "The roles and functions previously performed by the missing member may remain unperformed [See above case study 3, p. 60].

2 A substitute for the missing member may be obtained from outside the family [See above case study 1, p.51].

3 The roles of the missing member may be taken over by other members of the family [See above case studies 2, p. 55 and 5, p.72].

4 The social system may break up" [See above case study 4, p. 67] (Parkes, 1996, p. 100).

Parkes observes that not only a person's role, but also their bodily characteristics and behaviour can all "be affected by major loss such as bereavement" (Parkes, 1996, p. 94). And, Parkes believes, "change in the world's view of me are likely to be associated with changes in my view of myself" (Parkes, 1996, p. 97). The question which each of us has to ask ourselves when we find ourselves in a situation of loss is "Who is the real me? Am I the person I believe myself to be or the person the world believes me to be? Is there an essential, unalterable me?" (Parkes, 1996, p. 98). Working through the grieving process, if it is to find any kind of resolution, demands nothing short of re-creation. Yet, Pargament believes, "The extraordinary power of religion in coping lies not in its power to conserve or transform significance, but in its ability to do both" (Pargament, 1997, p. 270).

Conclusion

In seeking to explore various ways of understanding differing aspects of human experiences of darkness within the health care setting, it has been my intention, by collaging healthcare literature with case studies from praxis, to see whether any light may be shed on what appears to be at first debilitating and disabling chaos. The keeping alive of hope with the possibility of transformation, the adherence to a faith, the giving permission for people to be and become themselves, all of which take place within loving

relationships mirroring the unconditional love God has for his people, point to the enfleshing of God in situations of brokenness and weakness. From the study of these theological and clinical reviews, a research study was designed to explore the key questions that have arisen with people that have been involved in both of these fields. In addition, by way of investigating how the “dark experiences” underlying these questions are communicated and interpreted, assistance will be sought through the medium of music.

Development

Chapter 3

Research Study

Introduction

The experience which initially stimulated this research was an encounter with a member of staff in the middle of the night on the Intensive Care Unit who appeared to be suffering some kind of breakdown (see Introduction p. 10-11). Subsequent conversations with patients, both on the acute and mental health units, who talked of similar experiences of existential darkness, confirmed the necessity for this research to take place. The research undertaken in this chapter, adopts that particular characteristic of practical theology which incorporates “reflection upon lived contemporary experience” (Pattison and Lynch, 2005, p.410 - 411). It is gained through the medium of interview. My research adopts Gilbert’s threefold nature of social research: “the construction of theory”, ”the design of methods for gathering data” and “the collection of data” (Gilbert, 1993, p. 18). When collected, the data will then require analysis.

Research Question

The question which is central to this research is “In the context of healthcare, where is God in the dark place of human experiences?” In seeking to

address this initial question, a number of other questions also demand attention. These include: “How is God understood?” “What is a dark experience?” What is a dark experience within healthcare?” “Do people experience God in dark experiences?” “If so, how do they speak of such experiences?” Within the hospital setting, very little has been written on the ways in which individuals talk about experiences of illness, bereavement or loss that they have had in their lives (which can, in the case of those with a religious faith, include a sense of the absence of God) and the methods they use in trying to cope with them.

Aims and Objectives

Aim

The main aim of this study is to investigate how people talk about painful life experiences in the context of being cared for in hospital or within the community. This research will also explore whether the findings may have a direct application as to how more effective pastoral care (by hospital chaplains and the like) may be provided in the future.

Objectives

The main objectives of this research study are:

a) to explore the kind of language and metaphor used by those experiencing darkness or absence of God within healthcare settings;

b) to explore the kind of language and metaphor used within other situations when people have painful life experiences;
c) to explore whether a greater understanding of a) and b) can lead to a better pastoral and spiritual response by the chaplain;
d) to indicate possible tailored pastoral interventions in response to identified needs by those experiencing dark times in their life.

Research Methodology

In this research, note has been taken of the different ways that knowledge can be expressed, (propositional or type 1 knowledge and tacit or type 2 knowledge): the former being “based on rationality and transferability from one context to another” (Lee, 2009, p. 141 after Eraut, 1994); and the latter being “based on the thoughts and experience of the practitioner“ (Lee, 2009, p. 141 after Gibbons, 1994). Gilbert describes these knowledge gathering approaches respectively as “deduction” and “induction” (Gilbert, 1993, p. 23). In this study the former found expression through academic literature, the latter through case studies and interviews. Both types of knowledge are narrative based, the author and the interviewee telling their story in relation to the material they are presenting. Because of the multi-faceted nature of the material being studied, the research method used in this study collages qualitative research with theological reflection. Here, qualitative research is understood as being “multi-method in focus, involving an interpretative, naturalistic approach to its subject matter.... study(ing) things in their natural settings, attempting to… interpret, phenomena in terms of the meanings

people bring to them" (Denzin and Lincoln, 1998, p. 3). Theological reflection is understood as a three way conversation between a researcher's "own ideas, beliefs, feelings and perceptions; the beliefs, assumptions and perceptions provided by the Christian tradition; and the contemporary situation which is being considered" (Pattison, 2000(7), p.135). Use will be made of the Hermeneutical Cycle (Carr, 1997, p. 22 - 27) and the Pastoral Cycle (Green, 1990, p. 25 - 30) in such a way as to suggest a third way of reflecting theologically, that of the Meaning-Making Cycle which is explored below in Chapter 5. Whilst the research method employed in this study could not be described as pure action research in that interviewees did not play "an active role in designing and conducting the research" (Swinton and Mowat, 2006 p. 228), their illnesses, bereavements and/or abilities to communicate their dark experiences through the medium of music most certainly did.

Note has also been taken of the nature of objectivity and subjectivity and whether or not the role of the researcher is acknowledged as having a significant bearing on the research, as "the participant observer is involved not detached" (Fielding, 1993, p 164). This was of particular relevance to case studies and conducting interviews. Note has been taken of the potential for bias as any qualitative researcher needs to be mindful of "their own values and beliefs in their *choice* of research subject; their *conduct* of research and *engagement* with research subjects; their *interpretation* of these subjects' actions and words; and the *presentation* of their research," particularly what is included as well as what is omitted (my italics) (Lee,

2009, p. 63). In this study, the interviewees were all known to me either through my work as a hospital chaplain or through my being a musician. As a way of mitigating against this tendency, the reader of the research is able to draw their own conclusions as to the efficacy of the researcher's interpretation, as extended data arising from it can be found in the Appendix (Appendix 7). In addition, this research will also follow the good practice (often adopted in qualitative research) for data to be coded (with themes identified) by another independent person and then checked against those of the primary researcher with any differences discussed and agreement reached regarding the themes that have emerged from the data.

Finally note has been taken of the fact that “ethics and ethical practices must underpin all research” (Lee, 2009, p. 144 –145), most especially when this involves direct contact with human subjects. This was of particular importance as most of the subjects interviewed in this research were or had been unwell or recently bereaved. Because of the ethical issues raised through any interview procedure (most noticeably around issues of capability and consent, doing no harm, confidentiality and effective data storage), ethical approval was sought from the University of Manchester under whose auspices this research was begun, the University of Chester who oversaw the final part of this research, my local NHS Research Ethics Committee and my hospital's Research and Development Committee.

Selection of Sample of Participants

In order to get a cross section of experiences and precipitating factors, I sought a small but purposive sample of people drawn from three distinct groups (Appendices 3 - 5). These were: three Christian public figures (ordained and lay) who were currently working (or were working when the interviews took place), exploring with them how their period of darkness has influenced their public role (001- 003); three musicians (a composer, conductor and performer) who are currently in practice, investigating how they seek to interpret dark experiences, communicate them to others and explore the effects (if any) that these experiences have had upon themselves (101 - 103); and six patients (five of whom were in hospital at the time of recording) who have been identified as experiencing existential darkness (201 – 206). Because one of the interviewee's (203) had particular problems with her memory, this interview was conducted with her husband being present. His words, when cited, appear in italics.

Collection of Data

In order to ensure that, at the time of writing, the data to be worked with was current, relevant and contextual; the medium of the interview was used. This was chosen in preference to other data collection media, for example focus groups, because of the personal nature of the material being communicated. The interviews have taken the form of “standardised or structural interviews”. This approach was used, in preference to the semi-standardised” or “non-

standardised" interview as it minimized any "interview bias" and any "loss of meaning as a result of imposing a standard way of asking questions" (Fielding, 1993, p. 135-137). All interviews were taped and transcribed and checked with the interviewees for accuracy. Interviews were on average an hour in duration and took place for current NHS patients in a private area within the hospital complex. Other interviews took place at work or at home. A brief summary of the interviewee's illness or bereavement is given below.

Table 1 Interviewee's health or bereavement status.

	Interviewee's particular healthcare situations.
1	Leukemia (now deceased).
2	Death of wife through breast cancer.
3	Bowel cancer
101	Clinical depression
102	Death of father when interviewee was still a teenager.
103	(None acknowledged)
201	Kidney failure leading to dialysis.
202	Diabetes leading to the partial amputation of the leg.
203	Life-threatening bronchial pneumonia which led to a marked memory loss.
204	Heart attack resulting in memory loss.
205	Hip replacement which then became infected leading to readmission.
206	Breast cancer leading to chemotherapy and double mastectomy.

Factual information concerning the Christian public figures who had experienced periods of darkness in their lives (two, recovery from a life limiting illness, and one, the death of a spouse) was already in the public domain before my interviews with them took place. What was not was their

detailed reaction to it. Out of the three musicians interviewed, two talked openly about periods of darkness in their lives, one did not. All six non patient interviewees agreed to be interviewed at the first time of asking. The patient group proved far more difficult to select. The patients all undertook a H.A.D. (Hospital Anxiety and Depression) test to ensure that asking questions concerning their period of existential darkness would not have an adverse effect upon their health (See Appendix 6).

Because of the use of the H.A.D Scale, some patients who had initially agreed to be interviewed could not be, because asking the questions would be construed as adversely affecting their perceived sense of well-being (according to the H.A.D. scale). In order to find six patient interviewees, ten patients were considered in total. Two patients had to be discarded because their H.A.D. scores were too high (21 and 17 respectively), one patient changed her mind after being asked the first H.A.D. question, and one patient was discharged before the interview (which had been pre-arranged with staff) could take place. Prior to interviews taking place, informed consent was obtained as indicated in the research proposal. The Christian public figures and musicians were contacted via email. Patients were asked whether they would be prepared to take part in this research by a member of staff who was not the researcher.

Analysis of data.

In this study, following Swinton and Mowatt's definition, analysis has been taken to mean “a process of breaking down the data and thematising it in ways which draw out the meaning hidden within the text” (Swinton and Mowat, 2006, p. 57). Having been taped, the interviews were transcribed and then analysed, in order to identify any thematic links that might exist between them and to begin to formulate any major themes that emerged from the material as a whole. Fielding breaks this process down as follows: "Field note transcripts – Search for categories and patterns (themes) – Mark up or cut up the data – Construct outline (re-sequence)" (Fielding, 1993, p. 163). Key to this process is the sensitivity and the reflexivity of the researcher, the former referring “to the attribute of having insight, the ability to give meaning to data, the capacity to understand, and capability to separate the pertinent from that which isn't” (Srauss and Corbin, 1990, p. 42 cited in Swinton and Mowat, 2006, p. 57); the latter as “the process of critical self-reflection carried out by the researcher throughout the research process that enables her (him) to monitor and respond to her contribution to the proceedings” (Swinton and Mowat, 2006, p 59). To act as a counter balance in case of any over-subjective interpretation of the researcher, the selected themes have been independently reviewed. So that all interviewees are able to draw their own conclusions as to the efficacy of the researcher's interpretation, they have each been offered the opportunity to see a transcript of their interview and to receive a summary report of the findings of the study. To enable a wider audience to reach their own conclusions with regards to this research, it is envisaged that the results of this analysis may be published in a

professional health care chaplaincy journal at a later date. Initially forty themes were identified (see Appendix 7a). I then began to explore whether some of these initial themes could be combined. This produced a revised list of twenty themes of which fourteen would seem to be particularly important, although not necessarily the most significant (see Appendix 7b). In writing up these themes, other combinations suggested themselves, reducing the total number of theme categories to 10 as shown in Table 2 (see also Appendix 7c).

Table 2 Final theme categories.

Theme (c)	Topic	Frequency
1	Illness or loss leading to a reappraisal of priorities.	11
2	The unpredictability of what the future holds.	11
3	The public versus the private person.	12
4	The context of finding out about the illness / bereavement, its present context and the effect upon the self.	11
5	The positive and negative aspects of suffering .	11
6	Support – faith, music and people.	12
7	Isolation.	11
8	The illness / loss engendering a feeling of activity or passivity.	9
9	Coping strategy including grieving	11
10	Symbols and the ownership of meaning.	8

Results

1 Illness or loss leading to a reappraisal of priorities.

It appeared that the experience of being ill oneself or watching a close family member become ill (particularly if the illness resulted in their death) did lead to a re-evaluation of one's sense of priorities. One's sense of what is or what is not important changes, when criteria which are assumed can no longer be guaranteed. In the context of the Church of England, two dominant issues at the time of recording were homosexuality and women bishops. One of the senior clergy interviewed from the perspective of leukemia says, “I find the whole package of opposition to the ordination of women and...the gay issue just... I have lost patience with it” (001, p. 7). He believes rather that it is the country's “economic crisis...this is what we should be concerned about” (001, p. 8). For another senior cleric, as a result of witnessing the illness and death of his wife, he says, “There's been a realisation of my own mortality which affects everything.” (002, p. 11) It has led to him being “so aware of the danger of wasting time” to such an extent that “it has changed the way I work” (002, p.11). The interviewee who works as a healthcare manager, part of whose role involved her writing a Cancer Plan for her local area is also forced to acknowledge her own mortality when she says, “...like all cancer patients, I've got a well-planned funeral because I've had the time to think about it. And you do think about it” (003 p. 18). She would seem to be applying her professional task-driven skills to her own situation.

For two out of the three musicians interviewed, one had experienced a period of mental illness, caused in part by a marriage break up, the other a

significant family bereavement. For the former, it seemed vital to take time out for reflection in some form or other. “The whole of the experience of Australia” (where she travelled to give a lecture tour) “gave me a chance, again a bit like the psychiatric hospital has, to re-evaluate what was going on in life...I think I did need to go away so far for so long really.” This is given added poignancy as this also meant she was away from her children (101, p. 30). For the latter, the effect of her family bereavement has been so significant, that it has led to her constructing the temporal periods of her life around it as the determining factor. As she puts it, “I think there's been three,...[parts to my life]..., zero to 14 while Dad was still with us and there was that weird sort of, 5 years, 6 years, was it 6? 7, 7 years where I was still hanging around at home but Dad wasn't there and then came here and sort of, then began my life as an adult.” (102, p. 8)

Of the patients interviewed, one experienced his previously ordered life turned into chaos, compounded by him being overseas at the time, when he was diagnosed with kidney failure. “I was completely lost. I didn't know what dialysis was... who was going to pay for all this treatment I was getting in the hospital [In Saudi Arabia]?..... I thought well there is the job gone, I'll be going back to UK” (201, p. 3). Too many unknowns seemed to crowd in upon him. Another patient, facing up to an amputation, sees this, not so much as an ending but a new beginning when he says, “I've lost my foot, which is a shame I suppose although in some ways I think “Good riddance to the wretched thing !” because it was, it was not fit for purpose...I just have to get

on with it now and learn how to walk again on a prosthetic limb" (202, p. 5). For a patient suffering from severe life-threatening bronchial pneumonia which had led to a marked memory loss, a reappraisal of priorities seem to result from looking forward rather than looking back. She acknowledges, "I was a bit angry... I don't know why I've gone all through this. I don't know at all....[Now] it has all changed. I mean now I know I'm on the way, I'm ready. I hope I go home very soon" (203, p. 3-4). Of another patient suffering memory loss, this time as a result of a heart attack, it was the memory loss itself that directly affected the ability to reappraise because of an inability to process data. For example he says, "I couldn't remember that I'd decided to put in for early retirement... the fact that that's been granted came as a complete surprise to me but a great relief" (204, p. 7). For another patient, the change of priority manifests itself in a move from inward-looking despair to outward-focused hope. She puts it thus: "...a couple of weeks back...I just felt that I just couldn't go on any longer with just laying here with no light at the end of the tunnel and then it turns round and then there is light at the end of the tunnel but you've got to help yourself to get there" (205, p 6). A young mother diagnosed with breast cancer observed, "...we did...make a conscious effort to be a bit nicer to each other...and... also just try to enjoy things more and not ... let the daily life get you down" (206, p. 8).

Born of a frustration with that which no longer seems important (seen through the lense of a person's mortality), a sense of order emerges. Out of

that which at first appears chaotic, endings are perceived as beginnings and new hope dawns.

2 The unpredictability of what the future holds

This theme can be seen to relate closely to theme 1; indeed the unpredictability of what the future holds can itself lead to a reappraisal of priorities. Even if there is a feeling, as an interviewee put it, that “you become much more humble when something appalling happens” (103, p. 15) there can be a real danger here that this is seen as somehow justifying the appalling thing happening in the first place. One interviewee saw the nub of the problem as this: “....how long have I got,” versus “talking about a potential cure” (001, p. 2). Another's wife tackled the doctor who had diagnosed her breast cancer head on. “Is this a death sentence?” “No, of course not!” “ (002, p. 2). As this was a patient who subsequently died, this questioned the doctor patient relationship and the importance of the doctor being able to give a diagnosis in such a way that it enables patients and those closest to them to plan for all contingencies that may lie ahead.

However the unknown causes its own problems. That which is uncertain is uncontrollable in any way. Two interviewees reflected similar emotions, the one saying “I was scared ... about the diagnosis ... I was desperate for my children...I was going into what was unknown territory for me” (003, p. 9); the second “when I was. .. waiting to find out I just felt really ... scared and ...

worried about the children ... worrying if I wasn't going to be around anymore" (206, p.3). Another patient having prepared for one healthcare episode is suddenly forced to consider another. As she describes it, "It started out as a straightforward hip replacement... which got infected and after seven days the whole thing burst open and I was back in hospital" (205, p. 1). Something which should have incapacitated her a few days, led to months of hospitalisation. There is a sense in which the illness is in control of the patient rather than vice versa. One response is to run away. One interviewee seemed undecided on how to proceed, whether to indulge in the tactics of fight or flight. People undergoing a dark episode in their lives "don't need to be cheered up, they need to get through whatever the pain is and really feel it to then improve" (102, p. 28). But she goes on, "I think there's a lot to be said for escapism" (102, p. 29).

Uncertainty about the future can be understood to rob you of any sense of the future at all or it can increase your determination, the proverbial problem always seen as an opportunity. Thus can be said by one interviewee, "sometimes you don't think you've got any future... you're just... waiting for the next thing to go wrong....now I enjoy things I mean just, you cut down your expectations" (201, p. 13). Yet another indulges in fighting talk when he says "I am absolutely determined to walk out of here like anybody else. And I don't see why I shouldn't...The alternative was to spend the rest of my life sitting in a wheelchair totally dependent on other people and I refused to do that." (202, p. 5) For another patient, early retirement gave a framework in

which to locate a future free of the constrictions of a pressurised job. As he puts it, “I was a bit shocked (but) it was probably a greater shock for the family than it was for me.” (204, p. 3)

Uncertainty about what the future holds is compounded for those with memory problems for whom there is also confusion as to what the past has been. In order for immediate family living on the mainland to have a sense of what had been happening, the husband of one patient explained, *“Every time I went home I used to give a bulletin to my children on the mainland... I used to write it down.. I've got a book at home, a diary, you know, of all the reports.” (203, p. 4)* This was read by the patient herself as she improved and began to recover her immediate past history. But there is always the pragmatic approach: “you've just got to think about it in a real logical way – anything can happen to anyone. So in a way even well people should be trying to cram everything in their lives because no one knows what's around the corner” (206, p. 11-12).

Finding oneself in unknown territory (which is made significantly worse if one has been has been given false hope by an assurance that all will be well), in addition to leading to the contrary responses of anger and acquiescence, can lead to a renewed sense of one’s own humility.

3 The public versus the private person

This theme, perhaps understandably, was seen as having an additional dimension by those who had a particular role to play within the public sphere rather than those who had not. One patient did acknowledge a public dimension to her illness. She noticed that "...when you are going through something like this you do talk to other people … who are going through similar things... because I didn't seem to suffer with many... side effects ….I was ... more upbeat so I ...feel like my story perhaps lifted other people" (206, p. 7). This resonates with Wilson's view that a true understanding of "health" can only be explore(d) from within" (Wilson, 1975, p.117). For those in public life, as well as the effect upon themselves of sharing this news with others, was the effect it would have upon those with whom it was shared and for whom they felt a certain degree of responsibility. Thus of the two clerics interviewed, one says, "Right from the word go, we decided that we would share information with our church members" (002, p. 3). The other wonders whether he might have been over zealous in his openness: "I was quite clear, everybody should know straight away and almost to the point of overkill I think" (001, p. 6). Lambourne believes that this information sharing can have a positive effect as only "he…who is joined to the suffering of others" is capable of wholeness (Lambourne, 1963, p. 162). Of the interviewee who has a leading role within a public organisation, she struggles in telling close family members and is only led to tell staff because of mistaken information about her condition (that she was suffering from a nervous breakdown) being gossiped abroad. She recounts, "...it was very difficult to tell friends...I couldn't tell my husband....I felt obliged to put

something into the (staff) newsletter.. I gather that the organisation felt a bit rocked by it “(003, p. 5, 8).

This responsibility of processing difficult information (either from one's own life story or from musical compositions) can also be seen to be at work amongst the musicians interviewed. For one in seeking to repair a fractured family relationship she says that to help “in the reconciliation process...I wrote a song to my Mother... I sing that, - as part of the show...People bring their own suffering and hang it on that” (101, p. 20, 22). Something which starts its existence in the private domain can also be used a vehicle for liberating others. It can lead not just to “*restoration to function in society*” but “*restoration to purposeful living in society*” (author’s italics” (Wilson, 1966, p. 17, 18). Another similarly can use the public realm in which to work through personal difficulties. For her, “...coming to University was very difficult... I...had a lot of issues with anxiety when I was younger and depression... (but) For me performance is where my passion is...I'm quite a different person” (102, p. 7, 12, 13). Whereas Lambourne and Wilson see an individual’s health and wellbeing worked out in a communal dimension, another musician, talking particularly about how one effectively conducts the music of others, believes there is a need to hold one’s own emotion in check. For him, “there are less and less pieces that I feel very emotional about.... (as a conductor) you also have a job of work to do” (103, p. 20, 21). This last point resonates well with those who are conducting funerals who need to keep

their own emotions in check in order to allow others to grieve for the person who has died.

Some patients interviewed seem to have found it helpful to have been open about their illness with friends and family from the very beginning. One says, “I was in the golf club...! just told people what had happened ...we just had a laugh about it because most of the others had something wrong with them” (201, p. 5-6). Another, “I told them right from the start.... friends, family enormously supportive. I've never concealed it from anybody.” (202, p. 6) A further patient commented, “...since that...initial...day on which I was taken ill, obviously the family were the first to know and...subsequently close friends and it has gradually spread outward” (204, p. 4). Two patients felt that in effect, they had no choice about telling people. One was missed by her church friends, as she and her husband explained, ”It wasn't kept quiet was it? My illness. I was missed”*. “They wanted to know where you were”. “So they asked me”. (*203, p. 5). The other had certain practical arrangements to put in place. “I did have no choice at all because then I had to put all sorts of things in place like carers for my sister. And when you walk around with a bright pair of blue crutches it’s pretty obvious that something is drastically wrong.” (205, p. 3)

At the heart of any pastoral encounter lies the dilemma of what should be shared and what should remain private, the sharing of any information which

burdens them suggesting that it is not being coped with and resolved privately. As soon as anything is shared with another person, a move from the private to the public sphere begins to take place. That in turn raises the question “How public is the pastoral encounter?” If that requires some liturgical working out, “How public should that be?” It raises the further questions of “How should the pastoral carer manage the material shared within the pastoral encounter or facilitate a liturgy?” “Should they share anything of themselves in the process?” In short, this journey along the continuum from the private to the public and vice versa raises questions concerning boundaries and the management of pastoral space to which I shall return in Chapter 5 which looks at the space where meaning-making takes place; Chapter 6 which explores the idea of the chaplain as the boundaried space in which pastoral music-making takes place; and Chapter 7 which looks at the actual provision of pastoral spaces.

4 The context of finding out about the illness / bereavement, its present context and the effect upon the self

Illness and bereavement do not happen in a vacuum, they arise out of the context in which the rest of one's life is set. How one is experiencing one's life at the time is bound to affect how one processes what is likely to be the life changing nature of the illness or bereavement upon the self. One interviewee remembers that, “When we were told that… (my wife)... needed another scan, there was a stunned silence...It was simply too difficult to talk about. Horrible.” (002, p. 1) But it was when his family was in the midst of a

great celebration that his wife's condition deteriorated as he explains, “On the day of the wedding of one of our daughters, my wife had pins and needles in her legs...Half way through the service she lost the use of her legs.” (002, p. 3) Thus as well as the worry about his wife, there is the additional concern about upsetting what should have been the happiest day of this particular daughter's life. Furthermore, his wife's eventual death affected the way that he reacted to others who were ill, for he had realised that he had convinced himself that all illness always leads to death, ruining everything, like it ruined his daughter's wedding. “When someone close to you *has not* recovered from an illness, you need a person that *does* recover from an illness to restore your faith in the possibility of recovery.” (002, p. 7) He desperately needed somebody who was ill to get better.

For another interviewee, the illness came at a time of change for his wife and himself. He records, at the time of the diagnosis “we'd only just put down an offer and negotiated a retirement house with a mortgage... because my mother died the year before...so we were living in a kind of impasse” (001, p. 5). And the diagnosis seemed to come as the result of a medical afterthought. “And as I left his (the doctor's) room, he said, ‘oh by the way, you might as well have a blood test.’...They did blood tests and ...they told me you'd got acute myeloid leukaemia” (001, p. 1). As the illness caused more uncertainty concerning the wisdom of continued working, certainly in his public role, the buying of a retirement home seemed increasingly fortuitous. But, in having to retire early “Planning for my retirement made me

think about the ageing process in general as a process of continual pruning, each bit of life preparing you for the next part that was to come." (001, p. 13) The death of his mother, moving out of being in full time work and facing up to the possibility of dying himself seemed to place his history within the wider history of humanity itself lived within finite time.

Does where a patient works, the function they serve and the role they play within the workplace or organisation affect how they are treated? If it does, can that be helpful or unhelpful? This was a real concern for one interviewee who was convinced, "I got different treatment because of who I am in the organization." (003, p. 4) It was certainly speedy. "...they brought me in for an endoscopy and by 2pm on the Friday afternoon, I knew that I had cancer, I just didn't know how bad" (003, p. 2). Whilst, on one level, it was reassuring to know that she was getting the best help available within the quickest time, there was a worry about how fair this was to other patients. But she found the additional problem that because a number of the staff were friends, including the clinicians who were directly responsible for her care, they found it difficult to speak honestly about the full implications of the diagnosis. She comments that the surgeon "kept saying he felt sure it would be OK...I couldn't allow myself to buy into his optimism" (003, p. 4). But she believes that having been a patient in the organisation in which she is a senior manager has made her more demanding in the standards she expects from colleagues. In her opinion, "I think my reaction to people and my expectation

of standards of care has risen. I can't be doing with poor care, I can't be doing with poor attitude." (003, p. 20)

For two of the three musicians interviewed, a period of debilitating illness, bereavement or breakdown in a relationship led directly to periods of creativity. Whilst the latter in no way justifies the former, for both of them there is the feeling that these two experiences are inextricably bound together. As one said, "my father died when I was 14 ... I lost a very dear friend of mine to suicide when I was 18... a couple of years ago I was in an abusive relationship" (102, p. 3,10). Yet, "...if I'm happy I can't write anything at all. I have no creative, not an ounce of creativity in me but actually it's at the dark times in my life that I find it starts to flow" (102, p. 6). And for one, through creativity, came hope. "I had.. two small children, a dying mother at that time, a dead father and a dying mother-in-law." I was "very ill in the hospital, composing those pieces... based on Julian of Norwich who I was reading at the time" (101, p. 28). In the midst of her suffering, "suddenly to find 25 pieces, I thought '... maybe life isn't always going to be like this... there is life beyond all of this lot, and I can compose'" (101, p. 29). For both interviewees their composing is only half of the creative process; the second part comes from performing the pieces that they have written. For one of these interviewees, "performance is where my passion is" (102, p. 12).

It was understandable that for those interviewed who were currently unwell at the time of being interviewed, the context in which their illness occurred was still very fresh in their minds. For some this was a sudden event, as one patient explained, the “heart attack...is a surprise in as much as I always thought I was reasonably fit” (204, p. 3). For some, although sudden, their illness may be attributable to the negligence of others. For a hip patient, “the infection came from the operating theatre... it was in the cement” (205, p. 1). A patient's husband was worried that the deterioration of his wife's condition did not appear to be noticed by the staff who were looking after her. She was taken ill at her nursing home with “*bronchial pneumonia”. “She was then in a state of unconsciousness.”* (203, p. 2) For another patient, the origins of his present healthcare worry goes back some years. When he explains, “11 years ago... I had somehow broken my little toe... being a Type 1 Diabetic this injury then caused the other bones in my foot to collapse to deteriorate. That resulted in an infection and an ulcer.” (202, p. 1-2) For a further patient, the context of her own diagnosis was that it occurred while she was still mourning the death of her mother from the same illness. “I was obviously quite worried about it because I had previously lost my mother to breast cancer” (206, p.1).

The effect these healthcare episodes had upon the patients concerned seems to have been affected by a number of factors such as: their memory; whether or not they have dependents; their anger at being unwell; and their ability to move on and look to the future. One interviewee found that her

illness increased opposite tendencies within herself. “I think I've got a lot more compassion now for people but then also ... when people really moan about nothing I find that quite irritating now” (206, p. 9). However, if you cannot remember the onset of your illness, it is hard to progress from one's view of self as being well to unwell to well again because of the gap that exists in one's perception of self. One patient is very clear, “I don't have perfect recall of all the decisions that I'd made prior to my admission.” (204, p. 7*)* “I was completely oblivious of anything. Now whether that's because I didn't experience it or whether it hasn't gone into memory at all is another question.” (204, p. 2)

For the two patients whose illness seems to have been the result of negligence, one feels that she has no choice other than to strive to get better as quickly as possible. “I had to totally adjust to what's happened...it has very much... interfered with my life because I look after my sister who has had a stroke.” (205, p. 2*)* The other finds it hard to let go when she recalls, “they told me I was trying to blame everybody...I suppose it was because I wanted to know why I had been so ill... I was a bit angry” (203, p. 3*).* For another patient, the life changing nature of the illness upon him serves to make him more determined than ever when he remarks, “I wish it hadn't happened. Of course I do but it has and I have to deal with it” (202, p. 11). Indeed, he seems to have been able to be quite stoical about his illness. “I just accepted it.... there's nothing anybody could have done to make it better...There was no anger or bitterness whatsoever. “(202, p. 4-5)

One response to finding out that oneself or a loved one is ill is silence, another is frustration, yet another is increased creativity. A person's ability to process the knowledge of illness is affected by past encounters with illness, its causes and its outcomes.

5 The positive and negative aspects of suffering, and the danger of too much as well as too little care

a) Its positive aspects

It was repeatedly noticeable how those Christians working in public life did not see their illness in isolation but seemed interested in exploring how their own vulnerability could empower others embarking on their own particular healthcare journey. No one is automatically immune from this experience. But even one of the patients interviewed who would not describe himself as having a public profile wanted to place his experience in the public domain. "I'm keeping a day to day diary on my experiences and I want to get it published...in order to help other people who are going to go through this after me.. and to inspire them." (202, p. 9)

A Christian leader talking about his wife's healthcare experience in a hospital ward, noted that because his wife "was visited by the bishop, the archdeacon, the rural dean and the chaplain (who brought her 'a hand held

wooden cross'), it was clear to the (other) patients that she 'was a woman of faith'" (002, p. 5-6). This could have been an unwelcome pressure but as it happened, it enabled his wife to minister to some of the other patients on the ward, "the hand held crosses which she received herself, she gave to patients who drew great comfort from holding them" (002, p. 6). It's as though a faith genuinely held in weakness empowered others and allowed honest searching conversations to take place.

For one of the musicians interviewed, there seems to be a sense that suffering could not be allowed to have the last word, that in the midst of suffering "there must always be hope". For her, this led to the creative process, in whatever medium one was working in, assuming a redemptive function. As she puts it, "as a creator you need to have hope in your heart...suffering always had to be transubstantiated" (101, p. 36, 38). Another, in response to her father's death says that she "wrote some very beautiful poetry; because her father was a priest, this ended up being called 'Slightly Yellow Dog Collars Under My Bed'". She tells of how she kept these dog collars until the smell of her father's aftershave was no longer present. She recognises how for an artist, maybe for others too, the "grieving process" needs necessarily to be "perfomative" (102, p. 17).

Other positive aspects to arise out of being ill oneself had to do with a better understanding of what others felt like when they were ill, a reminder of the

value of people and of good health. Thus for one patient, her illness has “made me feel a lot closer to my family” (206, p. 11). For another, undergoing a major health scare enables one “to sympathise more with people...if they've got a long term type illness.... because you realise that they are in a similar state to you” (201, p. 8). A patient's husband is able to say of church friends before and after his wife was taken ill, *“It seems to me that it’s when you're really ill, not much is said prior to that but suddenly you realise the value of this person”* (203, p. 7-8). Of two other patients, one believes their illness enables them to look forward to a time when they expect not to be ill. “Mentally I'm feeling you know, good, positive, looking forward to getting home and sorting a few things out there.” (204, p. 12) For the other, because she has coped with her illness for so long, it is almost as though she believes that it can contain no more nasty surprises, and so her attitude towards it has “been very positive because of the infection that I first encountered... it's been with me rather a long time so I could never look at it negatively” (205, p. 6).

b) Its negative aspects

Suffering clearly has the potential to propel the sufferer into a very dark metaphysical place indeed. For those in the public eye there can be the dangerous assumption, that somehow they will be given the wherewithal to deal with this nightmare. The truth of the matter is that they are as likely to be frightened as anybody else. What they do bring to the situation is their ability to articulate their experience. One feels that “there have been stages in the

illness when I have felt beyond the community, beyond the church, beyond the faith and actually at times, beyond myself" (001, p. 13). Another cannot think of the organisation in which she plays a leading role, but of her family. "I was scared...I was desperate for my children" with the added realisation that this horror will never truly end as "I'll never be cured of cancer, I will only ever be in remission!" (003, p. 9, 11) Another public figure talks not just of his wife's suffering, but of his own utter helplessness. "One night, (my wife) spent a night in real turmoil, experiencing 'a dark night of the soul'. - But I'm alright now. - I can remember thinking ;What the hell is happening here?'" (002, p. 4).

Suffering can be so bad at times that all the sufferer can think of doing is to actively seek to end their own life. One of the musicians interviewed gives a glimpse of this when looking back from a position of relative tranquility in her life, talks of a hymn she wrote containing the line " 'A death with joy and peace', which was very different from the sort of death I had planned for myself when I was ill!" (101, p. 30-31) This can be compounded by the hallucinogenic side effects of certain medication "the sort of hallucinations... (where)... all that...I kept saying...(was)... 'Why?' 'Why?' That was my word. I didn't want it, they were awful. There was no reason" (203, p. 9-10). This lack of control over one's situation that suffering so often produces was picked up by another of the patients interviewed who said, "it is at times the lack of feeling that you have any control over what's going on around you and that can be trivial or it can be something quite major and significant" (204, p. 12).

This lack of control can manifest itself as lack of certainty concerning future healthcare outcomes as “it's always at the back of my mind 'Will it (the cancer) come back? '” (206, p. 11). For one patient, a major lack of control was the direct consequence of another's mistake “They had to then remove the hip ... so I was then bedridden ...(for)... thirteen months.” (205, p. 1)

Past suffering can also destroy one's present reality, so for one interviewee, “That grieving process, that personal side of me... that I am always very honest about but I don't really want it to colour how people feel about me.” (102, p. 17-18) There is the feeling that you need to be careful who you tell what to about yourself, and how much you tell them. Suffering can have the effect of robbing you of part of your present and your future, of robbing you of the things that you enjoy most. So one interviewee has come to the conclusion, “I don't go to golf club anymore because... it always looks so beautiful and...I begin to feel envious.” (201, p. 12) It can be that hospitalisation brings you face to face with the suffering of others which can be harder to process than the implications of your own healthcare difficulties. One interviewee put it thus. “The only thing that I really didn't like, that upset me about the treatment was seeing other people suffer and also seeing people dying in the ward....It's something you never get used to. “ (202, p. 4)

Suffering can be experienced in a positive way if the sharing of one’s experience of suffering, and/or the continued ability to live the life of faith in

the midst of suffering, can empower others. It can be experienced negatively as loneliness, helplessness and the theft of one's present and one's future.

6 Support – faith, music and people

a) Support from one's faith

For some interviewees, there was the importance of the community of faith, which was sometimes underpinned by some form of liturgy. For others, it was the importance of favourite passages of scripture / hymns that was key. For one interviewee whose illness often meant that he had to be in medical isolation, it was very important knowing that he was being upheld by "the community of faith. And whilst I've not been able to go out and about... (my wife)...and I have been able to celebrate the eucharist together." For him, as an ordained person, there was also the importance of "Maintaining the priestly life....I'm taking the spiritual winter with me, into that spiritual summer." (001, p. 10) Another valued being part of Christian community when he could not pray openly himself. "We knew we were upheld in prayer...On that Saturday night, there were no verbal prayers spoken between us. Words seemed out of place somehow. We both held hands and prayed independently." (002, p. 4) Another person interviewed explained that his prayer life had grown out of a sense of loneliness. "I've always said my prayers actually, since I was a little boy...this is because I was always, sort of, alone,... I was an orphan since I was six, I went to boarding school, then I joined the Air Force." (201, p. 10)

A further interviewee had only re-established links with her church community shortly before her illness was diagnosed. Being part of that community gave her a familiarity with some psalms and hymns. She recounts, “I have a faith, I'm Catholic, cradle Catholic. And I've had a bad time... But I got back to church about a year to 18 months before all this hit the fan.” (003, p. 17) A significant source of support during her illness was a hymn based on Psalm 92 and especially the words, “And he will bear you up on eagle's wings, not let the fowler snare you...I got more comfort from that I think, than I did from anything else.” (003, p. 17-18) Another found it was two books of prayers that sustained her, firstly “a book with little bits of scripture...a book for people entering into a more spiritual way of looking at life and how to find quiet.” Secondly, a book containing “some of...(my husband's)... “favourite prayers” (203, p. 8). Her husband is in no doubt, “*I'm very conscious that God has been with us right from the start.”* (203, p. 9)

Certain psalms were among those things from which a further interviewee drew strength. She listed amongst that which gave her support as the writings of “Julian of Norwich...(and)... Hildegard of Bingen”. Furthermore, “...the psalms of complaint are very important and I prefer them for complaint rather than lament.' (101, p. 4, 34) She also began to see pain as an experience that could draw somebody closer to the divine. She says, “I believe often one does experience some of the deepest joys in some of the hardest bits....in a sense one is approaching the source of ultimate ministry

which is in a sense the life of Jesus where you know the joy and pain are inextricably bound together really and the two are caught up together." (101, p. 40) This would seem to be borne out by another interviewee who felt that his illness, and the planned amputation to remove part of the leg that was causing him all the problems, deepened his sense of spirituality. "It's (my illness) increased my faith without any doubt what so ever. I feel I've been given this unique opportunity to get my life back...well at the end of the day well what can I say, except 'Thank you God for everything' ." (202, p. 10)

For two further patients interviewed, one found regular contact with chaplaincy helpful in helping to bring some kind of pattern to his hospital stay. He explains, "My faith and what's in it I think has been a source of considerable comfort and...support...having the Christian structure within the hospital has been a great comfort. Seeing you... the Sunday gathering... that's been a good fixed point and a much valued fixed point in the weeks." (204, p. 8, 12-13) Another speaks of how important it was for her spiritual well-being that she could look out of the window and remain in touch with the world 'out there'. "...every day I lay here... but through one window I can see a tree and I look at that tree and more often than not my prayers go to that tree" (205, p. 5).

b) Support from music

As one of the musicians interviewed commented from the audience perspective "There's no question that music can lift the spirit and sometimes

(quite the reverse as) a jolly good... weep..(can).. let the floodgates open." (103, p 38) Another describes the therapeutic effect of performing itself when she says, "using performance to extricate some trapped emotion is really effective" (102, p. 16). For one of the patients interviewed, it was the achievement of making music. He explains, "I am a very keen campanologist...If I don't think I can do something I won't do it, and if I do something that's because I think I can do it and know I can do it." (202, p. 6 - 7)

Music without words can be particularly significant for those who are struggling to find a form of communication that can help them articulate the 'dark place' in which they find themselves and speak to them in the midst of it. One interviewee, whose public life in ordained ministry depended on the use of many words, found himself admitting "I come to realise the inability of words to communicate the deep experiences of life." (002, p. 10) This has the potential for implications far above the immediacy of the particular situation in the way that he exercises pastoral care as a minister within the church. For others, music exists as a vehicle to carry words more effectively. This was the experience of one interviewee for whom the words of a particular psalm were made more meaningful for their metrical treatment as a hymn (003, p 17).

It is not surprising that music plays an important role for each of the musicians interviewed. In the case of two of them, music used as a medium for better expressing the words (or in one instance, expressing philosophical concepts) is key, especially: “Julian of Norwich, Hildegard of Bingen...Sydney Carter in the area of the protest songs... Cage for engaging philosophy with music... the English folk song...the English hymn tradition” (101, p. 3, 8-11); also “Sacred music...Irish music,..world music...opera and classical music, (and) lots of Baroque music.” (102, p. 3) For the third, it is music for its own sake that is the primary driver. “I can't live without this, I can't...It's sort of essential. It's amazing. It became eventually the only thing I really felt I could do and wanted to do.” (103 p. 4, 1)

One of the musicians interviewed talks about her belief in the redemptive power of music. (101, p. 32-33). She gives the example of how music can be a bridge to past memories and can act as a healer of wounds. In describing how she had had a bad relationship with her mother who had subsequently died, she tells of a friend who “wrote an incredible song... about his father who had abused him” (101, p. 17). This inspired her to compose and sing a song to her long dead mother. This interviewee concluded that “the song distances you from the emotions...It’s a holding form and once they're held in some form they are more manageable” (101, p. 19-20).

Sometimes it would seem that it is the musical composition that conjures up a particular mood, sometimes the mood that can find release in the remembrance of a piece of music. Another interviewee acknowledged, “For me, music was so important, music both with and without words. Especially the music of Bach. In hospital, I had Classic FM on most of the time. I'd listen to this once...(my wife)... had gone home in the evening. I probably fell asleep with it on.” (001, p. 14) Sometimes, the greatest gift music can offer is that it is not silence and by its very existence in sound in the present moment, affirms that the listener is not alone. As one other interviewee proclaimed, “Music is not a luxury, it is an essential, and if people are not music-making, there's something gone out in their life.” (103, p. 29)

c) Support from people

Those interviewed seemed to find support from three sources: family and close friends; hospital staff; and lastly, members of associations to which the interviewee also belonged and of the wider community. One interviewee remembered “my husband was absolutely fantastic because he'd just... he was always.... no matter how down I felt he would always... be positive” (003, p. 15). For another her husband also played a key role in her recovery . He “used to come up every day for me... and I don't know what I would have done without him” (203, p. 1). A further interviewee indicated just how difficult receiving support from the closest of family members could be as a judgement is required in just how much support should be given. “My wife,

she just soldiers on and sometimes I think she wants to do a bit more for me than I really need." (201, p. 7)

For some interviewees, their support came from more than one member of the family, my "wife, sons have done as much as they possibly could have been expected to do" (204, p. 4). Another says, "my husband and my children have really kept me going" (206, p. 6). One interviewee responds "Without doubt, my biggest support has been that of the immediate family... I felt very supported by my colleagues who'd shared the journey with me." (002, p. 9) For another in her grief, it was her university professor who was key. "She's just a fascinating woman who has been an enormous inspiration..through discussion that we've had about... painful experiences...She's been an enormous influence on my life." (102, p. 23) For one interviewee, as well as family members, the carer, who became a friend by the frequency of her visits, also had a key role to play (202 p. 8). A friend played a significant role for one interviewee as "she'd been diagnosed with bowel cancer about 18 months before me" (003 p. 7). For another "all my friends really supported me ... my best friend being one of the chemo nurses...up in the chemo ward" (206, p. 6).

In terms of staff, key support given came from a number of different professions. For one interviewee in a pastorally caring role himself, there was an initial problem in allowing himself to be ministered to by others. He

tells how one of the hospital chaplains in particular “helped me to sort all sorts of things out that needed to be sorted out about my life and my past” (001, p. 6). Another recounts how “a couple of NA's (nursing auxiliaries) were truly outstanding...They represented normality in the midst of chaos” (002, p. 5). One NA in particular was given high praise by one of the other interviewees in passing. “There was (support) and mainly from the nurses in here... I was told by the surgeon 'you would hit rock bottom at one stage' and that happened actually a couple of weeks back...And the first person that came in was one of the auxiliaries.. ‘Come on ... you know, we're going to get through this together’.” (205, p. 4)

In terms of the wider community, there was support from a sports club and church community. One interviewee describes how at the golf club, “ one of the other gentlemen, his wife had had a transplant and so it was easy to talk to him because he understood what I was talking about ” (201, p. 6). For another, that which was important was knowing the she remained part of her church community even though she could not be physically present at it. “I knew I had a lot of people thinking about me and praying for me.” (203, p. 1) Another remarks, “the prayer support was absolutely crucial. But in addition, “there were the meals turning up on the doorstep” (002, p. 9).

Whilst support is understood to come from the three distinct groups of faith, music and people outlined above, there are a number of occasions when

these support categories merge. Aspects of the community of faith and worship such as psalms and hymns can be sung. Members of the community of faith can be amongst those providing the most practical of support.

7 Isolation

A major side effect of illness or loss is the sense of being separated from those who are well and who have not been recently bereaved. For some this can be so pronounced that they become mentally as well as physically unwell. One patient remembers an uncharacteristically low and isolating period in her condition which was broken by an observant nursing auxiliary (205, p. 4). It was the assurance that she was not alone that seemed the key factor. For one of the church leaders interviewed, the clinical isolation, necessitated by the need to protect his own fragile immune system, seemed almost like a metaphor for the isolation he felt from the his church authorities. There seemed to be no mechanism for pastoring the leading pastors of the church. So he comments, “I was always in my separate room and nearly always in an isolated room where you had to go through one door and then through another, so I didn't have very much to do with other patients.” (001, p. 12) But he also says, “I don't think the church has really grasped that… (church leaders) …have to find their own support.” (001, p. 6) Whilst the former isolating experience is unavoidable, the latter very definitely should not be. Another leader in public life found that when she was in her management role she was noticed, when she walked down the main corridor

in the hospital. When she walked down as a patient, wearing more informal clothes, she was not. “I've become one of the invisible ones.” (003, p. 10-13)

If illness or grief is one of a number of things affecting one's sense of wellbeing, one's sense of isolation and inability to effect any change for the better in the situation can be compounded. Another interviewee says “...one thing after another seemed to go wrong” (002, p. 5). He recalls, “I definitely felt anger at the radiographer and the doctor. I remember feeling an incredible frustration at the time, a feeling of utter helplessness.” (002, p. 7) For one of the current patients interviewed, it was being away from home when receiving his diagnosis and not understanding its implication that seemed to make him feel so alone. In his words, “…I was completely lost. I didn't know what dialysis was, no idea” (201, p. 3). For another patient it was her memory loss that made her feel so frighteningly disorientated as her husband makes clear, *“...when she came round... she was completely disorientated for at least 2 weeks... and after that time, when I came in she said ‘I want you to sit down here a minute... and tell me why I am here,’ and that was the day when she 'came back”* (203, p. 3).

Of two of the musicians interviewed, one records, “I got married and had children and continued working ... then (I) got quite depressed...in the middle of the depression the marriage failed.” (101, p. 3) The other remembers that“...coming to University was very difficult... I was enormously homesick

and I also had a lot of issues with anxiety when I was younger, and depression" (102, p. 7). The third musician draws attention to the isolating role that some musicians find themselves in, particularly that of a conductor when he remarks, "Musicians are quite insular...you also have a job of work to do." (103, p. 29, 21)

Isolation can unwittingly be self-inflicted by a desire not to draw attention to oneself or be a nuisance. One patient remembers that "Several people looked round at me... and I ... screamed in pain. And this man asked me if I was all right and being brave as usual I just said 'Oh yes, yes I'm OK' when I should have asked him to call an ambulance." (202, p. 1) One patient chose to comment on his perceived isolation of other patients on his ward when he says, "Many rely on sons, daughters, grandsons, granddaughters who might be distant and not immediately available and you sort of identify their sense of unavoidable isolation from the family." (204, p. 7)

A general sense of isolation can be compounded by clinical and pastoral isolation, by a public persona being acknowledged yet a private one being ignored. It can be further compounded by a lack of information and faulty memory. It constitutes an extreme example of negative suffering, where that which is private is unable to be worked through in the company of another (see sections 3 and 5 above).

8 The illness / loss engendering a feeling of activity or passivity

Striving to come to terms with a difficult diagnosis can produce variously a feeling of activity or passivity within the patient or their immediate family. For those driven to having to 'do' something', because the prospect of 'doing nothing' feels that one simply isn't 'pulling one's weight', seems to be based on the unspoken assumption that the more you 'do', the more chance there is of either yourself or your loved one 'getting better'. One patient, favouring activity over passivity, said that “I had to be strong for everybody else” and continued, “there's always something to do that you don't actually get a lot of time to think” (206, p. 3, 11). Another interviewee said, “Our youngest daughter...was over recently and is determined to arrange a concert in London this September in aid of Leukemia research.” (001, p. 12) One patient, because of his own immobility, seemed to want the staff to be more active on his behalf in order to increase his chance of improvement. “I've felt frustrated...when you're in process, in training of doing something and because ... there are other calls upon nursing staff, they wander off and do something else, you know it might be a quarter of an hour before you're attended to again.” (204, p. 5)

One interviewee found he had no choice in being caught up in activity, because so much about his deteriorating condition seemed such hard work. He describes “it was a real battle between me and the Podiatrist they'd say ‘No you mustn't walk on your foot, you mustn't walk on your foot’ and I'd say ‘I can't help it I have to, I have no choice’.” (202, p. 3) Another found the

language of battle singularly inappropriate to describe her illness as it implied that you were able in some way to change its outcome, preferring to see this as a matter of at best chance or at worst fate. “People write about fighting the battle with cancer. I don't agree with it. I don't agree, because there is no battle to be fought, because you've lost…. You've either won from day one or you've lost from day one.” (003, p. 14-15)

Amongst those who felt the need for less activity in trying to come to terms with the death of his wife was the man who confessed, “I've become less religious...My prayer life is more simple,” He discovered “the importance of resting with your faith rather than running with it” (002, p. 12). Another found the space that she needed to process various life events in a specific method of transport in commenting, “I do find that travelling away on planes very useful... I've written some really good things in airports... you're in a...strange subliminal space really.. you're not really anywhere.” (101, p. 25) One interviewee found that, for her, music was the catalyst that gave her space and enabled her friend to know that “all would be well”. “Through music... we manage to get by without saying anything... just by there being the presence of music that we knew meant something to one another even if it was ...(a)...slightly different interpretation, she knew... that I was OK.” (102, p. 24)

Some interviewees were able to recount how, in time, their loss or bereavement led to a new beginning. One, having lost her faith, whilst not

regaining it, rediscovered an interest in theological debate. She remarks, “I am almost more interested in the concepts of various different theologians now that I've actually come to terms with where I sit with God and certainly where I sit with Christianity” (102, p. 22). Another, having been fitted with a new leg after amputation, proclaims, “I feel I've been given this unique opportunity to get my life back... I feel in a non-religious sense 'born again'.” (202, p. 10) One interviewee, beginning to focus on the quality of her life, regardless of its quantity, explains, “We bought a house in France as a result of everything that happened....we always thought that when we retired, we'd buy a house in France.” (003, p. 15) Now that her illness is in remission, she continues, “I'm going to retire next year a couple of years early.” (003, p. 20) Most strikingly, one interviewee describes how the seeds of “meeting a mate” were sown the day that his wife was taken seriously ill when all three were attending his daughter's wedding - the person who was to become his new wife, being his son in law's mother (002, p. 9).

Illness seems paradoxically to produce both an increase and a decrease in the activity of the patient and those close to them. On the one hand, there is a sense of having to be strong, of raising funds to support research, of battling on, even when not knowing whether the battle can be won or lost. On the other hand illness can lead to being less overtly religious, yet seeking liminal spaces in which new beginnings can take shape.

9 Coping strategy including grieving

a) Coping

Interviewees seem to cope with their illness or loss in a variety of ways. Some, both within and outside a faith perspective are bluntly realistic about facing the possible outcomes of their illness themselves and in the way that they sought to prepare family members. One reasoned “It’s either going to be the end, or back to normal or early retirement.” (001, p. 5) Another took the position, “I accepted it, once I realised that it wasn't going to improve” (201, p. 4). 'Dealing' with his wife's illness in the context of family life another asks then answers his own question. “How did we cope? I think there was a kind of silent acceptance of reality. The hard thing was having to tell the girls.” (002, p. 2) One found herself coping differently with her own illness to the way she reacted to her husband's subsequent health scare. In the case of my own illness, “I never bargained with God...I always thought, ‘Just give me a bit of dignity to get me through this. Don't let me down on that’. But, funnily enough, a couple of years ago, when my husband was admitted to Coronary Care and we didn't know quite what was going on, I bargained with God then.” (003, p. 18)

For one interviewee it was important to write things down. “It is a very therapeutic thing to do.” (202, p. 9) For others, it was the support and generosity of those around them. One patient's husband recalls, “w*hen you became aware of what had happened to you and what was being done for*

you your words to me were that you were so grateful (that) so much attention (was) being given to you." (203, p. 4) For another, it was her elderly brother and sister with whom she lived. "We've done very well, the three of us…there is only the three of us left in the whole family." (205, p. 3) Another recognised that being in control for her was an important coping mechanism. "I am a bit of a control freak and I find it very hard to let things go ... I wanted to just carry on as much as normal ... I felt if anyone took over from me then I would almost just crumble." (206, p. 8)

A number found humour helped. This includes laughing at oneself, at the situation and how others might deal (or not deal) with the situation. So one interviewee, in seeking to deal with the effects of her chemotherapy, comments that "my husband and my children have really kept me going and made me laugh at my weakest moments. Like laughing when I've got no hair" (206, p. 6). Another says "I don't have perfect recall of all the decisions that I'd made prior to my admission... you've just got to live with that and make a joke of it and be cautious in what you say...you don't know what you don't know." (204, p. 7) Another comments, "...it's not like a mental illness...(it's)... very visible. My nickname is 'Hip-less' " (205, p. 4). Laughing at the situation, a patient remarks, "...we just had a laugh about it because most of the others had something wrong with them. In fact we even suggested instead of us going to visit the doctor's he should come to the golf club once a week!" (201, p. 6). And then one is able to say of her mother and

her illness, “If my mother was alive, this would have killed her!” (003, p. 9) Humour, it seems, has the power to take away the power of the illness itself.

For two of the three musicians interviewed, perhaps not unsurprisingly, music itself forms a major part of their coping strategy. One made the point that “If one is a survivor oneself of things... the thing that you have, of course, is lots of techniques...You need a sort of personal song really.” (101, p. 20, 26) The other observed that “...it's at the dark times in my life that I find it (creativity) starts to flow” (102, p. 6). Music seems to create a safe place in which a dark experience can be articulated.

b) Grieving

Whilst recognising that one can grieve at other losses, not simply loss precipitated by a person's forthcoming or actual death, for those diagnosed with a life limiting illness, the grieving can begin at the moment of diagnosis and continue before, through and after their death (see Chapter 2 above). Thus one bereaved interviewee says, “I think I did a lot of my grieving before... (my wife)... died.” (002, p. 9) For those who have worked in the public realm, their illness and death affects more than just the family and close friends of the deceased. The wife of the same interviewee was a teacher. He explained how the children whom she taught had to be helped to express their feelings openly yet constructively. The school “had a quiet room for the children to go when they were feeling upset where they would

write beautiful pieces of work that were stuck on the wall" (002, p. 8). In terms of his own and his daughter's grieving, he recounts "The girls' reaction to their mother's illness and subsequent death has been one of utter shock." (002, p. 7) He continues, "We were all there around the bedside when.. (my wife) was dying...(There was)... a sense of just 'loving loss'. It has bound the girls together with a what I can only describe as a kind of ferocity....But none of us are able yet to talk about the death scene." (002, p. 9) This feeling of recognising the depth of an emotion but finding oneself unable to express it, was mentioned by another interviewee when she says, "sometimes I think when you're grieving you do get to that point where you just cannot cry any more but you need to" (102, p. 9).

Those seeking to cope can be pragmatic, silently accepting of the situation and helped to do so by the support of those close. They can laugh. They can refuse to bargain with, or actively seek to bargain with God in an attempt to invoke the help of someone who they perceive can affect the situation for the better. They can write down their experience of illness or bereavement, they can create. Or they can fail to cope, meeting the situation with silence, which requires some metaphorical or symbolic unlocking.

10 Symbols and the ownership of meaning

Mention has already been made of the relationship between the subjectivity and objectivity of the researcher (see p. 83-84 above). This holds equally

true for the person recounting an experience and the person listening to it being recounted. As one interviewee said, “because I feel so well ... that's a sign to me that everything is OK” (206, p. 11). The present reality clearly has a filtering effect on how one processes what one is experiencing. One of the interviewees acknowledged “The Subjectivity of Interpretation” asking “Whose Meaning is it Anyway?” (102, p. 19). In performance this raises the interesting concept that the meaning of any experience is nobody's private property. Meaning is 'free-floating”. Once placed in the public square, it belongs both to everybody and no-one. As this same interviewee continues, “If I've shared something with you then it’s no longer just mine, it actually becomes yours to interpret how you wish.” (102, p. 21) What the recounter of the experience retains is the choice of what and what not to share and with whom. In talking of the death of her father, she points out, “....there are certain things that I wouldn't want to speak with them (my grandparents) about because...it would just be too much. I mean that's my perception. That's my interpretation...it would make them too sad” (102, p. 26).

Sometimes the difficulty of recounting painful experiences is born of an inability to attribute meaning to them. As one interviewee said, “I don't know why I've gone all through this.” (203, p. 4) Sometimes metaphorical language, “seeing one thing *as* something else….and using the better known as a way of speaking about the lesser known” can help (McFague, 1983, p.15). This is particularly so when it’s been, in the words of one interviewee, “a surprise... a bit of a shock...a bolt from the blue” (204, p. 9-10); when the

experience seems beyond the scope of words in common usage to aid its retrieval. One interviewee who recognised a loss of control by her healthcare problem and the need to “go with the flow”, felt that “ ...once you're kind of on the roller coaster you have to just keep going until you get to the end” (102, p. 27). Another, who acknowledged the need for some kind of stability in the midst of the chaos of his illness, was comforted “...to know that within this crazy existence...both (the) personal one and the organisational one there are a number of fixed points that you can tie your rope to” (204, p. 13). Yet another (as has already been mentioned above on p. 112) felt the need, both relational and spiritual, in the midst of being in hospital, to retain some kind of contact with the outside world (205, p. 5). The patient who had part of his leg amputated used this link with the outside world to enable him to reward himself for all that he had been through, a “carrot” in contrast to a “stick”. He puts it thus, “I'm going to get myself a Tibetan Terrier as a reward partly for being ill all this time... and it would do me good, not just emotionally but physically as well.” (202, p. 12)

Interviewees all seem to recognise the importance of retaining a sense of hope, even when their abiding experience was of darkness extinguishing all light (see Kubler-Ross, 1970, p. 112). Sometimes this seemed impossible to achieve. But as one acknowledged, “...a couple of weeks back...I just felt that I just couldn't go on any longer with just laying here with no light at the end of the tunnel and then it turns round and then there is light at the end of the tunnel but you've got to help yourself to get there” (205, p.6). Two of the

musicians interviewed spoke very graphically about discerning hope in apparently hopeless situations. Drawing upon Old Testament imagery, one talks of how “...out of the wilderness will come the water” and how “...the place of the crack is the place of the greatest beauty” (101, p. 34, 33). The second musician talks of the insights shown by a woman who was, to all intents and purposes, perceived as being disabled. He explains, “She wrote me a poem... which was called Jesus Christ the conductor... she'd watched rehearsals and she'd compared perhaps preaching and teaching to conducting.” (103, p. 28) In Chapter 6, I shall explore whether the conductor might also be a helpful symbol for the pastoral carer.

Sometimes mere words can seem inadequate in facilitating experiential interpretation and so for some, the use of symbols - pegs on which to hang, and through which one can interpret, meaning - can be of assistance. A symbol “both organizes the immediacy of the experience and ‘makes its strange’”, gives it a particular association (Williams, 1983 p. 283). One of the interviewees articulates her belief in God's abiding presence, of being held by God, and after Mother Julian of Norwich, her belief in the God who affirms that “I will hold you in the hollow of my hand...that notion of being held” (101, p. 35). What is of more value is a loving husband holding the hand of his wife especially in her more bewildered moments and willing her back to health. He asks,*“...can a person think spiritually when you 're in that state of hallucination?...I don't know... whether spirit can talk to spirit in these circumstances I don't know but I went through the motions”* (203, p. 11). For

another interviewee, for whom the loss of her father led to a loss of faith (a loss which seems to be compounded by the fact that her father was an ordained Anglican priest), churches retained a sense of the numinous and were places of safety (102, p. 2). It may be that being in church helped her feel closer to her father in a similar way that (as was noted above on p. 106) keeping one of her father's old dog collars under the bed did (102, p 17).

The most powerful symbol to emerge out of these interviews was that used by one interviewee to describe the death of his wife comparing this not to the death of Christ, but the final meal that he shared with his disciples during which he washed their feet. “We were all there around the bedside when my wife was dying, a kind of last supper, our six daughters and their partners. In the final moments there was a sense of just 'loving loss'. It has bound the girls together with what I can only describe as a kind of ferocity.” (002, p. 8)

Meaning is interpreted subjectively, the present context processing prism-like what one is experiencing. Symbol and metaphor can help unlock meaning by re-contextualising it to retain a sense of hope, rather like a conductor drawing music out of the living instruments of life, or the death of a loved one washing the feet of those dear to them with the waters of eternal life. Meaning is free floating and belongs to those with whom it is shared.

Limitations of Study

Whilst producing a wealth of research material there are a number of limitations implicit in the research method chosen. These can be itemized as follows:

1 The sample size was small, and it was taken from a limited geographical area which, because of the population's largely monochrome cultural and faith makeup, exhibited no multi-cultural and multi-faith features.

2 The research sample was opportunistic, I could have chosen different public figures, musicians and patients with different healthcare or bereavement experiences.

3 The use of "standardised or structured interviews" could be said to limit freedom of response by the interviewee (Fielding, 1993, p. 135-137).

4 The use of an inductive rather than a deductive research method means that its findings have to be "based on the thoughts and experience of the practitioner" (Lee, 2009, p. 141 after Gibbons, 1994) and cannot automatically be transferred "from one context to another" (Lee, 2009, p. 141 after Eraut, 1994).

Conclusion

In this chapter, I have introduced and analysed the data and focused on specific themes that have arisen as a consequence of this research study and analysis of its findings. I have looked at the kinds of language and metaphor used by people who are experiencing, and/or seeking to communicate, times of existential difficulty. This has enabled me to explore

further within the context of health care, how one can speak of God in the dark places of human experience. A number of metaphors and symbols have proved helpful to the various interviewees. These were seen as being of assistance if they enabled meaning to be attributed to the experience of illness or bereavement, and by so doing, enable people to retain a sense of hope. As McFague reminds us, metaphors and symbols both permeate Jesus' own ministry, the former through his "parables of the Kingdom", the latter through his "sacramental language" and actions (McFague, 1983, p.14). For us too, as we speak of, and strive to make sense of the reality in which we are situated "*many* metaphors and models are necessary, … a piling up of images is essential, both to avoid idolatry and to attempt to express the richness and variety of the divine-human relationship" (McFague, 1983, p.20). What is required is a collage of sensory inputs.

The findings of this chapter would seem to point to the fact that, as has been noticed in previous chapters, the only way that God can be believed in with any credibility, is by being seen to be involved with, and supportive of, humanity in the midst of its suffering, in a wisdom born out of lament. But praxis underpinned by theological and clinical literature is not the only way of engaging with this topic. Music, with its metaphorical qualities, also offers a powerful medium for its further exploration, which will be addressed in the following chapter.

Chapter 4.

God in the darkness - Musicological Review

Introduction

Having gathered data both from the academic world and from praxis as to just what shapes the "dark places" of human experiences, and explored what role God might play (if any) within them, this chapter explores the language that people use to communicate God's presence or absence in their own dark experiences. Because so often this communication takes the form of symbol and metaphor, my suggestion is that this process is viewed through the prism of music, its use as a dialogue partner reflecting the "interdisciplinary approach", which Pattison and Lynch believe is integral to any practical theological research (Pattison and Lynch, 2005, p.410 - 411). Arising out of his work on dementia, Goldsmith reminds us that for some, "Words can be confusing. Words relating to religion can be even more confusing, and words relating to religious experience can be the most confusing of all." Rather than seeing this as a problem, he regards this as an opportunity for new insights, new understanding (Goldsmith, 2004, p. 143). It leads him on to suggest that there needs to be an openness to using non-verbal as well as verbal communication that reaches out to a person's inner being and the patience to explore "what it is that brings solace, satisfaction, hope or meaning to people", what it is that enables their "being" to have a sense of "wellbeing" (Goldsmith, 2004, p. 143 -144).

To see whether music can indeed provide a meaningful language through which people can communicate the presence or absence of God, I shall consider five musical compositions, each of which, either by virtue of where they were composed and first performed or through the compositions themselves, juxtapose received tradition alongside lived experience. By engaging in critical dialogue and theological reflection they generate new insights concerning both (after Pattison and Lynch, 2005, p. 412, 415 – 418). These are: “Quartet for the end of time” by Olivier Messiaen; “Child of our time” by Michael Tippett; “The War Requiem” by Benjamin Britten; “Collage : In Memoriam Charles Ives” by Gregory Clifton-Smith and “Space for Peace” by June Boyce-Tillman. The reason for choosing these particular pieces is that each was either written during, or addresses issues arising out of, periods of war or social fragmentation. The contexts which led to the composing of the first three compositions has been fully documented elsewhere (see Pople, 1998, p. 1; Tippett, 1991, p. 39; MacDonald, 1997, cited in Britten 1997 p. v). “Collage” was composed in 1973 in preparation for marking the one hundredth anniversary since the birth (and twentieth anniversary since the death) of the American composer Charles Ives (1874 – 1954). “Space for Peace” was first performed on the eve of Holocaust Memorial Day 2009 in Winchester Cathedral. It has subsequently been performed on this day (27th January) and at this venue in 2010, 2011, 2012 and 2013.

In compositions such as these, as well as celebrating (and increasingly nowadays being horrified at) what is, and remembering what has been, composers, as indeed artists in general, are faced with two fundamental questions:

1 Is the artist's function simply to hold up a mirror to the world and reflect what he or she sees ?

2 Is the artist's role to encourage, to offer hope to a troubled world?

Pope John Paul II believed that it is the artist's vocation to “search for new 'epiphanies' of beauty so that through their creative work as artists, they may offer these as gifts to the world.... Even when they explore the darkest depths of the soul or the most unsettling aspects of evil, artists give voice in a way to the universal desire for redemption.” (John Paul II, 1999, quoted in MacMillan, 2008, p. 12) MacMillan himself believes that art can become “the bridge that will heal the wound of division” as part of this redemptive process (MacMillan, 2008, p. 12). If the language of metaphor in art can offer a way of communicating humankind's deepest joys as well as its deepest sorrows, perhaps art can be of help in offering pastoral care a model of discerning, communicating and moving through experiences of acute darkness.

Music both arises out of, and returns to, silence. Just as “silence is not of itself neutral” neither is sound; both can be perceived as being oppressive or liberating, God-denying or God-affirming (Winkett, 2010, p. 136). To know what kind of sound or silence one is being presented with requires

discernment on behalf of the listener, whether they also are the initiator of the sound or silence, or not. In this regard, it shows a marked similarity with the listening and discernment that lies at the heart of pastoral care. Within the hospital setting, the chaplain, in listening to the stories people “sing” both in isolation from, and in communion with, other “singers”, has the dual role (reflecting the two points above) which Winkett sees as falling to the wider church: Firstly, in “holding up a microphone to the patient's world view and replay(ing) what he or she hears”, the chaplain can act as “critical friend” (Winkett, 2010, p. 131). Secondly, as with point 2 above, in seeking “to offer hope to” persons caught up within “a troubled world”, the chaplain can help them to find their authentic voice, by calling “people into silence in the presence of God” (Winkett, 2010, p. 134). It is to the role of artist as reflector that I now turn.

1 The artist as reflector

In his foreward to Winkett's book “Our Sound is our Wound”, Rowan Williams, in describing her perception of the relationship between beauty and the fallen world, says, “If we are making perfectly harmonious sounds.... something is wrong” (Williams cited in Winkett, 2010, p. x). As Winkett herself points out, if we are to live authentically within the world, “the sounds we make...start to reveal deeper theological questions about who we are, of what we are afraid and in whom we trust” (Winkett, 2010, p. 3). She relates to the biblical tradition of lament which she describes as “both a protest against the pain of the present time and also a timeless expression of the

weeping voice of God in whose image and likeness we are made" (Winkett, 2010, p. 38). It is because she believes that "the sound is an audible scar of damaged tissue underneath", the sounds we make, (and presumably the sound we choose not to make) whether we use words or we choose not to, can be a window into, and a metaphor for, that which lies deep within us, rooted in our individual and collective past, propelling us ever onward, hence the title of her book (Winkett, 2010, p. 5). Fulkerson believes that "creative thinking originates at the scene of a wound. Wounds generate new thinking. Disjunctions birth invention…Like a wound, theological thinking is generated by a sometimes inchoate sense that something *must* be addressed" (Fulkerson, 2007, p. 13–14). Thus Fulkerson sees responding to a wound as a metaphor for theological thinking itself.

In music, this wound is represented as dissonance. It is dissonance that gives music its tension, the resolving of, and discovering of new dissonance that gives it its momentum. That which is regarded as consonance and dissonance, and the degree to which either is in the ascendency, changes with successive generations. Sometimes it is forces external to music that precipitate this change. For example, "After Auschwitz, it is not appropriate that before God, every cadence resolves, or that every rhythm is comforting" (Winkett, 2010, p. 34). But even then, a new song emerges, music is still possible. Boyce-Tillman firmly believes that "inside all of us, there is a musician trying to get out. That musician is our own healer and potentially, through us, the healer of others" (Boyce-Tillman, 2000, p. 282). In

addressing the issue of the painfulness and woundedness of humanity, she believes that “Pain can be regarded as cracks in a fabric that needs a right relatedness....The disjunctions are the wounds – personal, cultural and cosmic....The music produced is a record of the process of healing.” Not only can music offer a reflection of the disjointed world in which we live, entering into music making “offers the possibility of transformed and strengthened living” (Boyce-Tillman, 2000, p. 282). If responding to a wound is also a metaphor for music making, perhaps the making of music offers another way of thinking theologically. I will pursue this suggestion by examining my five chosen works in greater detail to see whether this analogy between doing theology and making music can be substantiated.

In Tippett's “Child of our Time” the sense of woundedness is most readily to be found in the setting of the spirituals. The spirituals provide Tippett with a central point of melodic construction, namely the interval of a minor third, which Bowen describes as being “produced so characteristically in the melodies of the spirituals when moving from the fifth of the tonic to the flat seventh” (Bowen, 1982, p. 44). Playing around with the sighing nature of this unresolved angst inherent in this flattened seventh interval, so crucial in jazz, seems to root this whole work in the collective wound felt by any oppressed peoples. Yet interestingly, singing with a consonant as well as a dissonant voice at times has appeared problematical. Winkett reminds us that one of the perceived difficulties with jazz was that “the same person would sing about faith in God and their experience of the world” (Winkett, 2010, p. 78).

But in fact, it is this dichotomy that becomes the musical wound, “wherein lies the jewel of great price” out of which new life springs (Tippett, 2007, p. 111)

Tippet's work in general is concerned with woundedness in his portrayal of the “nameless” perennial “scapegoat” (Bowen, 1982, p. 43). Yet within its three parts there is “a pattern of movement that takes us from the general to the particular and back again” (Bowen, 1982, p. 47). It is only in the middle section, for example, that the four soloists are named – soprano, the mother; tenor, the boy; alto, the aunt; and bass, the uncle. Some choruses have names too, such as “Double Chorus of Persecutors and Persecuted” (Tippett, 2007, p. 68-71; 59). Furthermore during the course of the work there is the feeling of movement from winter to spring, from woundedness to healing. The opening chorus begins with the words, “The world turns on its dark side. It is winter.” Part III begins with the words, 'The world descends into the icy waters' but significantly continues, 'Wherein lies the jewel of great price'- foreshadowing the new life which is to come, that would seem to be confirmed by the melismatic setting of choral writing (Tippett, 2007, p. 110-111). Before the penultimate “Ahs” which lead into the final spiritual, the choir sings “It is spring” (after Wilfred Owen's poem 'The Seed' (Bowen, 1982, p. 48)) (Tippett, 2007, p. 4-9, 145). Yet one gets the feeling that this journey from winter to summer is not linear but cyclical, the rhythm of nature providing a metaphor for humanity's fragmentation and reconciliation and fragmentation.

For Bowen the main theme of the oratorio is first articulated in movement six, the tenor solo, the central section of which, during which the voice sings, is set to a tango rhythm! (Tippett, 2007, p. 35) Here Jung's influence can be seen as it portrays “the psychologically divided Man, at odds with his Shadow” (Bowen, 1982, p. 48). Tippett himself describes this central theme in which: “The man tells of his psychological split self which appears to him and actually is on a certain plane the frustrations of his condition in the commonwealth. He has lost the relation to his soul.” (Bowen. 1980. p. 138-139 cited in Bowen, 1982, p. 48) The anger that this causes is projected onto others, hence the concept of the scapegoat. As Bowen points out, this divided self only finds any sense of resolution in the penultimate movement, number twenty nine (Tippett, 2007, p. 136), “where it is clearly and movingly encapsulated: 'I would know my shadow and my light/so I shall be whole'” (Bowen, 1982, p. 48). And then follows the affirmation of integration and new life proclaimed in the final spiritual. Or does it? The final spiritual “Deep river” ends in a musically unresolved way, again with a sighing minor third. Perhaps there simply is no answer to the issues Tippett is exploring.

For other composers, melodic “woundedness” is portrayed through the interval of the Tritone. This interval, because of its harmonic ambiguity and its difficulty in being able to be resolved satisfactorily, became known as the “devil in music”. Being neither the interval of a perfect fourth or perfect fifth, but halfway between the two, it screams out against the tonal system in

Western music, based as it is upon the cycle of rising fifths for sharp keys and falling fifths for flat keys. In Messiaen's “Quartet for the End of Time”, this device is one of the ways he contrasts what is from what will be. Thus in “Abime des oiseaux” (Mvt 3), written for unaccompanied clarinet, which is a movement full of contrast between slow and fast, sad and fun-filled, very soft growing in dynamics to very loud within a single bar (Messiaen, 1941, Bars 13 and 21, p. 15), and in which echo effects, widely and closely spaced melodies are much used; the interval of the tritone features repeatedly.

“Danse de la fureur, pour les sept trompettes” (Mvt 6), is another movement full of contrasts (Messiaen,1941, p. 23-35). It has a breathless quality and is extremely exciting, employing as it does an “ametric” (irregular) style of rhythmic writing, the metrical equivalent of woundedness, with much of it being loud and extremely fast. These sections are set alongside less hectic sections. Again there is a feeling that the tritone predominates (most particularly between F# and C), representing opposite tonal polarities (compare Messiaen,1941, Bars 1-4 with bars 5 – 8, p. 23-24, letter D – E, p. 25-26 and subsequent similar places).

But perhaps the most striking use of the tritione as musical wound occurs in Britten's “War Requiem”. One of the great ironies of the “War Requiem” is that the tritone is employed as a principal force for unity within it. Yet in this work, the 'un-peaceful' tritone interval of F sharp and C natural “always

appears in relation to the idea of “requiem”” (Evans, 1979, p. 452). It is the opening interval sung by the choir at the beginning of the first movement, “Requiem aeternam” ; it straddles the boys' material “Te decet hymnus Deus in Sion”; it exists between the harp accompaniment and tenor solo in the passage beginning “What passing bells”; it is in the closing tubular bell notes and dominates the concluding choral writing of the same movement (and that of the Dies Irae (2) and the Libera Me (6)) before the unaccompanied choir's magical resolution into F major (Britten, 1997, p. 1–2, 8-9, 16, 24, 90, 238). It is present in the choice of tonal centres in the Offertorium (3) vacillating between the C sharp minor of the boys' opening material and the G major of the choral fugue (Britten, 1997, p. 91 and 97). It pervades the Sanctus (4) in the opening percussion, soprano solo and chorus “fluttering” material, before the grandiose D major orchestral material (Britten, 1997, p. 140- 144, 145-151).

But does the “requiem” material provide a real resolution at the end of movements 1, 2 and 6 or not? Evans suggests that “this cannot be regarded as ‘the outcome’ in the long term (or even notably logical) sense of each of the three movements that cadence in this way” (Evans, 1979, p. 452). It is in the shortest movement of the War Requiem, the Agnus Dei, (5) that resolution is finally achieved. In this movement, the tritone interval provides the twin points of reference in the ascending and descending semi-quavers that variously pervade the choral and orchestral writing and the tenor solo (Britten, 1997, p. 170-178). Again the metrical equivalent of a wound, an

irregular time signature (that of five semiquavers to a bar) also emphasises an initial feeling of dislocation, in a similar way to the irregular time signature (that of seven crotchets to a bar) emphasises an initial feeling of dislocation at certain points within the Dies Irae (Britten, 1997, p. 25, 27, 30, 33, 72). Evans is of the opinion that despite its brevity, “only the Agnus Dei achieves a final statement of an equipoise in which the strains of the whole movement are balanced out” (Evans, 1979, p. 452). This is underscored by a coming together of the music to which Owen's poetry and the Agnus Dei is set and the sentiments of the words themselves. Owen's “greater love, and the liturgy's prayers for “requiem sempiternam”“ are reinforced by the addition of the words by Britten “”Dona nobis pacem” in the tenor's final melody (Evans, 1979, p. 452). So, not only at the centre of this movement, but at the centre of this composition, it is a musical “wound”, the tritone, that is used as a force for reconciliation.

The general sense of woundedness which permeates the whole of Collage, as with the War Requiem, is that caused by my desire for Collage to set text which proclaimed the presence of God, alongside text which proclaimed God's absence. I wrote this in memory of Charles Ives, a feature of Ives’ writing being to juxtapose disparate musical strands alongside one another, strands that could even be in different keys or in different time signatures (reputedly influenced by listening to approaching and departing marching bands of his youth). I decided, then, to make this the driving force behind Collage: the contrast set up between these two types of text and the musical

material that accompanies them is intended, Ives-like, to ask the un-answered question “Why?”

To this end, it uses differently constituted groups of musicians spaced around the audience, the different groups either being assigned different texts or remaining “text-less”. In addition to the live musicians, there are the three pieces of pre-recorded material for organ and choir (played through three separate speakers positioned spatially around the audience) which are settings of: Vaughan-William's “Psalm 150”, Merbecke's “Glory be to God on high” and the hymn “God moves in a mysterious way”. The climax of the work is when the lines, “God is his own interpreter and he will make it plain” are heard in isolation, followed by strident trombones. This in turn gives way to the return of the opening choral setting of I Cor. 13 and the “love” music. The questions posed here include: is life “a tale told by an idiot full of sound and fury signifying nothing” from Macbeth Act V Scene V or is it the greatest gift that God can give us? Are the different voices we hear throughout our human existence signs of chaos and fragmentation or signs of the rich variety of life in all its fullness and its possibility for healing and integration? Are they symbols of Babel or Pentecost? As the audience hears the various texts, the hope is that new meanings are generated through their various juxtapositions. Thus the question is not just “Why do we live?” but “How will God give us any idea as to why he has called us into being?” As was noticed with Tippett and Britten, the answer would seem to have to have something to do with love.

Music seems to lend itself to the holding together of opposites, irrespective of whether there is any resolution of these opposing perspectives. “Music, unlike any other art or discipline, requires the ability to express oneself with absolute commitment and passion whilst listening carefully and sensitively to another voice which may even contradict one's own statement” (Daniel Barenboim, 2008 quoted in Winkett, 2010, p. 77). Boyce-Tillman believes that one of the insights of music therapy has meant that “the process of integration can be seen as the state of the peaceful co-existence of diversity which can be encouraged musically by the use of diverse motifs and instruments” (Boyce-Tillman, 2000, p. 245).

But health and healing (and one might add, a sense of the presence of God) may be found not just through integration and within what one finds uncomfortable, but by pushing against that which one finds comfortable in order to explore pastures new (Boyce-Tillman, 2000, p. 14). Health, as life, (and again we might add, theological enquiry) she regards as a dynamic process, and thus eminently suitable to be symbolised by the dynamic art of music where adults as well as children can learn to play once again (Boyce-Tillman, 2000, p. 19).

2 The artist as a vehicle for encouraging and offering hope.

When performed, music in a very real sense exists in the present moment. It continually comes alive in each successive present moment. It offers hope in the very act of “being”. Because of it existing within a single moment and within time generally, Begbie sees music as “*enacting* theological wisdom”, a wisdom that is already in existence because God is already in existence, in the “dark” as well as the “light” places of human experience (Begbie, 2000, p. 5). He agrees with Rowan Williams that “What we learn, in music as in the contemplative faith of which music is a part and also a symbol, is what it is to work *with* the (temporal) grain of things, to work in the stream of God's wisdom.” (Williams, 1994, p. 250 cited in Begbie, 2000, p. 97) Because of its use of “delay and patience” and “promise and fulfillment”, music is a symbol for the finite *doing* world held as it is within the infinity of God's *being* world (Begbie, 2000, p. 127). It is not surprising therefore, that music is one of the vehicles favoured for worshipping God.

In such a composer as Tavener, Begbie recognises God's “beingness” breaking through into humanity's “doingness”, by the latter being suspended by the former. Tavener does this through using chant from the Orthodox tradition and sustained pedal notes or drones. Tavener believes, according to Begbie, that “Chants and drones form a kind of ‘umbilical cord’ to the sacred”; they are ‘sounds which are rooted, ultimately, in eternity in God’.” (Begbie, 2000, p. 136) The timeless quality in Tavener's music is also much influenced by the compositional style of Olivier Messiaen. As Begbie readily

acknowledges, the only way that Tavener, and other composers like him, can convey eternity in time is when “eternity (is) construed largely in terms of the “*negation of time*” (Begbie, 2000, p. 145). Thus it is in danger of becoming mere escapism if it leads one away from “the belief that God's eternity has been made known as accessible through a redemption which has integrally involved created time” (Begbie, 2000, p. 146). Drawing upon the music of James MacMillan, running through which is the strand of Crucifixion and Resurrection that proclaims “resolution of conflict, not just resolution” (Mitchell, 1999, p. 19 cited in Begbie, 2000, p. 150), Begbie concludes that “Eternity, as an expression of God's Holy Trinity, is ‘a fluid conjunction of simultaneity and sequence’”, the finite becoming fused with the infinite (Hunsinger 1991 Pg 56 quoted in Begbie 2000 Pg 153).

In dedicating “Quartet for the End of Time” “In homage to the Angel of the Apocalypse who lifts his hand towards the heavens and says: 'There will be no more time'” (Messiaen, 1941), Olivier Messiaen could be understood as joining in with what Winkett describes as the music of the angels, music which takes the form of a “kind of thunderous gentle melody that leaves you struggling to breathe because it has revealed the truth in an instant about love and beauty, loss and revelation” (Winkett, 2010, p. 103, 114). Fundamental to Messiaen's rhythmic style is his predeliction for Greek metre. One metrical foot “may be substituted for another- not necessarily of the same overall length”. Thus, “Instead of even beats and bars....Messiaen worked in effect with beats of irregular length”, compounded by incorporating

“added value” notes (Pople, 1998, p. 3-4). In addition to Greek metre, Messiaen “also made a study of classical Indian rhythms” making use of “regional rhythms” and the idea of “non-retrogradable (palindromic) rhythm”. As well as rhythmic innovation, Messiaen was also exploring new paths with his 'modes of limited transposition'. The evolution of these undoubtedly sprang from “his familiarity with the church modes” (Pople, 1998, p. 4).

In “Louange a l'Eternite de Jesus” (Mvt 5) , the slow cello part combined with the repeated chordal writing of the piano part, serves to generate a timeless quality to the piece. The soft cello harmonics at letter D add to its ethereal nature (Messiaen,1941, p. 22). In “Louange a l'Immortalite de Jesus” (Mvt 8) the lyrical violin part, for the most part employing triplet rhythm, contrasted with the throbbing piano part, dominated by second inversion E major harmony, again produces a feeling of timelessness. The low sonority to the piano notes (Messiaen, 1941, p. 50-52) contrasted with the very high violin writing at the end of the movement adds to this feeling of space. In “Vocalise pour l'Ange qui annonce la fin du Temps” (Mvt 2), the dropping of the clarinet part after just two pages, and the slower tempo leaves the unison strings ethereally playing ond martineau-like above repeated piano chords, and suggests once again a feeling of timelessness. Rather than focusing on the suffering of the times in which he is living, Messiaen chooses to focus on the majesty of God and the eternal dimension in which our transitory world is set. He makes clear “that this quartet was written for the end of time, not as a play on words about the time of captivity, but for the ending of concepts of

past and future: that is, for the beginning of eternity“ (Golea, 1960, p. 64 cited in Pople, 1998, p. 13). Messiaen's great message of hope is to remind a humanity imprisoned in time that temporality is itself located within an eternal reality.

For Boyce-Tillman, the offering of hope to a troubled world, is not to be found by looking ahead to the end of time, but by looking back beyond particularism to universalism, to that original goodness inherent within each individual, agreeing with Gill that “Incompatible... movements within as well as between faiths need ... enlightenment, the whole necessarily being greater than the sum of the parts.” (Gill, 2010, p. 416) Her “Space for Peace” is tapping into to the divine harmony of which Maurice speaks, “a divine harmony, of which the living principle in each of these systems forms one note, of which the systems themselves are a disturbance and violation” (Maurice, 1837, p. 308 cited in Gill, 2010, p. 418).

Boyce-Tillman's search for peace is set against the backdrop of genocidal horrors. With the exception of the first performance, the subsequent performances have all begun, after a moment of silence has been kept, with a short act of remembrance with prayers said and candles lit by representatives of the three monotheistic faiths, Jew, Christian and Muslim. Boyce-TIllman describes this composition as being “an exciting way to explore a new way of music and meditation”. It is “a musical vigil for peace”

(Boyce-Tillman, 2011, p. 1). In this composition, each group brings to the performance items that it wishes to perform. These are combined with chants which the composer has written, the juxtaposition of difference and sameness, variety and unity, present experience set alongside a future hope being a central concept of this work. Because every time the work is performed, different groups will bring a different selection of music to sing or to play, and these will interact with other groups' music in different ways, this composition can never be performed the same way more than once. It exists in time for a moment, and then is gone. Thus the composer is not a mere writer of notes, but a facilitator and enabler of the music making of others, a provider of “space” in which “peace” can be experienced. The composer as facilitator and enabler is an intentional approach on Boyce-Tillman's part as she believes than lasting peace can only be created from the “bottom up”, as the “top down” method so easily becomes one individual or group exerting power over another, a method which has been tried in the past and found wanting (Boyce-Tillman, 2011, p. 2).

She believes that music can indeed be used as a force for reconciliation as it can symbolise healing and wholeness by stressing the importance of inter- and intra-connectedness, “within the body, human being to human being, humans to the natural world, human beings and the natural world to God or the spiritual” (Boyce-Tillman, 2000, p. 10). This view of music, which stresses the intuitive over the rational, stands counter to the prevailing “Western post-Enlightenment culture” in which the reverse is the case (Boyce-Tillman,

2000, p. 10). She believes that a balance needs to be struck between these two types of knowledge, as she maintains that “All ways of knowing lie within each individual, ...they can be validated through music-making…(So)…Music making potentially becomes a way of challenging the dominant value system, as well also of supporting it” (Boyce-Tillman, 2000, p. 13). Thus Boyce-Tillman encourages us to discover, or rediscover, our own unique voice.

Conclusion

This chapter has explored the use of music as a language that can be used to communicate God's presence or absence in various dark experiences. It has looked specifically at whether the artist's function is simply to hold up a mirror to the woundedness of the world and reflect what he or she sees, or to offer hope, by discerning the infinite breaking in upon a finite troubled world. In addition to the artist passively reflecting what is seen or actively offering hope, art can provide a structure for framing this encounter. To this end, I shall explore in Chapter 6 below whether elements of musical compositions, particularly their form, have anything to say to us concerning the way that praxis and tradition can be held in relationship one with the other, “living human instruments” re-interpreting and re-creating the music of God (Stevenson-Moessner, 2008 p. xiii).

The search for God (holding up a mirror to the world and reflecting what is seen), and the God for whom one searches (the offering of hope to a

troubled world), seems full of dialectical imagery of darkness and light in persistent *collage* (Fulkerson, 2007, p. 13–14). Both seem characterized by antimony which "simultaneously admits the truth of two contradictions, logically incompatible, ontologically equally necessary assertions" and which "testifies to the existence of a mystery beyond which human reason cannot penetrate" (Bulgakov, 1937, p.116 cited in Garrison, 1982 p. 27). Could it be that antimony provides the way of discovering the pearl of great price after which we all seek, a rediscovering that the finite is indeed set within the infinite?

Each of the works considered above, either through where they were composed and first performed or through the compositions themselves, juxtapose received tradition alongside lived experience. Messiaen sought to place his concentration camp experience within an eternal perspective. TIppett and Britten, both pacifists themselves, demanded some kind of response from received traditions when faced with the horrors of war. Boyce-Tillman searches for unity in diversity. My piece looks for a meaning beyond the statement of opposites. If "theological thinking is generated by a sometimes inchoate sense that something *must* be addressed" (Fulkerson, 2007, p. 13–14), as Garrison has said of philosophy and theology, so, I believe, the same can be said of music and theology, that "both … cohere in a living dynamic relationship, keeping their respective identities, and yet producing a synthesis greater that either of their parts" (Garrison, 1982, p.59).

It is possible that the way that music functions helps us better understand how practical theology functions, especially as it finds expression through the medium of pastoral care. This will be further addressed in Chapter 5. In addition, I am also suggesting that music can provide a model for discerning, communicating and enabling people to move through periods of darkness. I shall return to this point in Chapter 6.

Recapitulation

Chapter 5

Synthesis

Introduction

This research has so far traced a path which indicates that belief in God can only have any credibility if God can be seen to be involved with, and supportive of, humanity in the midst of its suffering. Clearly this is not a new theological insight, but what it does underline is that those who experience periods of profound darkness in their lives have to embark on a journey from loss of meaning to meaning-making, a journey which discovers wisdom emerging out of lament . Having been thrown into a time of existential crisis, as they begin to try and make sense of what is going on in their lives, they are brought into contact with those world views which for the person of faith, will include sacred texts and the wider faith tradition. This may prove immediately helpful, and meaning may dawn once again. But if this fails to engage with where people find themselves, as the majority of interviews undertaken in this research has suggested, this juxtaposition of opposing world views can exacerbate loss of meaning. What it can also do however, is to begin a reaction arising out of these opposing views that needs to be articulated and heard by someone else as the existence of a reality that lies beyond that which is immediately apparent is glimpsed. Within the hospital setting it is often the chaplain who strives to hear what the patient has to say

to them. This requires not just attentive listening to what *is* being said but also to what *is not* being said (in musical terms, the rests), and what is being said metaphorically.

As the (patient's) need for conceptual and existential reorientation takes hold, this may require a response which needs some kind of attentive working out liturgically, which will not invariably require a public act of worship in the chapel, but could be carried out privately with patients at their bedside. It may not need any overtly religious liturgy at all but some more secular "acting out". This will either lead to some kind of meaning being discovered or a loss of meaning still pertaining, in which case opportunities need to be created for this cycle to begin again. But it is not exclusively the chaplain who is the primary hearer of the patient's yearning for meaning-making, so part of the role of the chaplain is also to facilitate this process in others.

Drawing upon the Hermeneutical Cycle applied to the text (Carr, 1997, p. 22-27), and the Pastoral Cycle, applied to situations (Green, 1990, p. 25-30), in which each successive new approach to a text or pastoral situation is shaped by previous experiences of looking at it, and reflecting upon it; this meaning-making journey can be expressed in the form of a Meaning-Making Cycle and be summarised as follows:

Meaning / Loss of meaning, → Juxtaposition / Correlation, → Attentive (metaphorical) listening, → Attentive (liturgical) working out / Performative theology, → Loss of meaning / Meaning. These three approaches within literature can be juxtaposed and compared in the following table:

Table 3 Cycle Comparisons.

Hermeneutical Cycle (Carr, 1997, p. 22-27)	Pastoral Cycle (Green, 1990, p. 25-30)	Meaning-Making Cycle (Clifton-Smith 2013)
"approach the text"	“experience”	Meaning / Loss of meaning
"get inside the text"	“exploration”	Juxtaposition / Correlation
“become involved in the meaning"	“reflection”	Attentive (metaphorical) listening
"be transformed"	“response”	Attentive (liturgical) working out / Performative theology
"prepare to approach the text anew"	“new situation” which must be experienced afresh,	Loss of meaning / Meaning

These three models advocate practical ways of “doing” theology by each looking at the interplay between Scripture, Tradition and Reason, (“the three pillars on which Anglican thinking rests” (Carr, 1997, p. 22)).

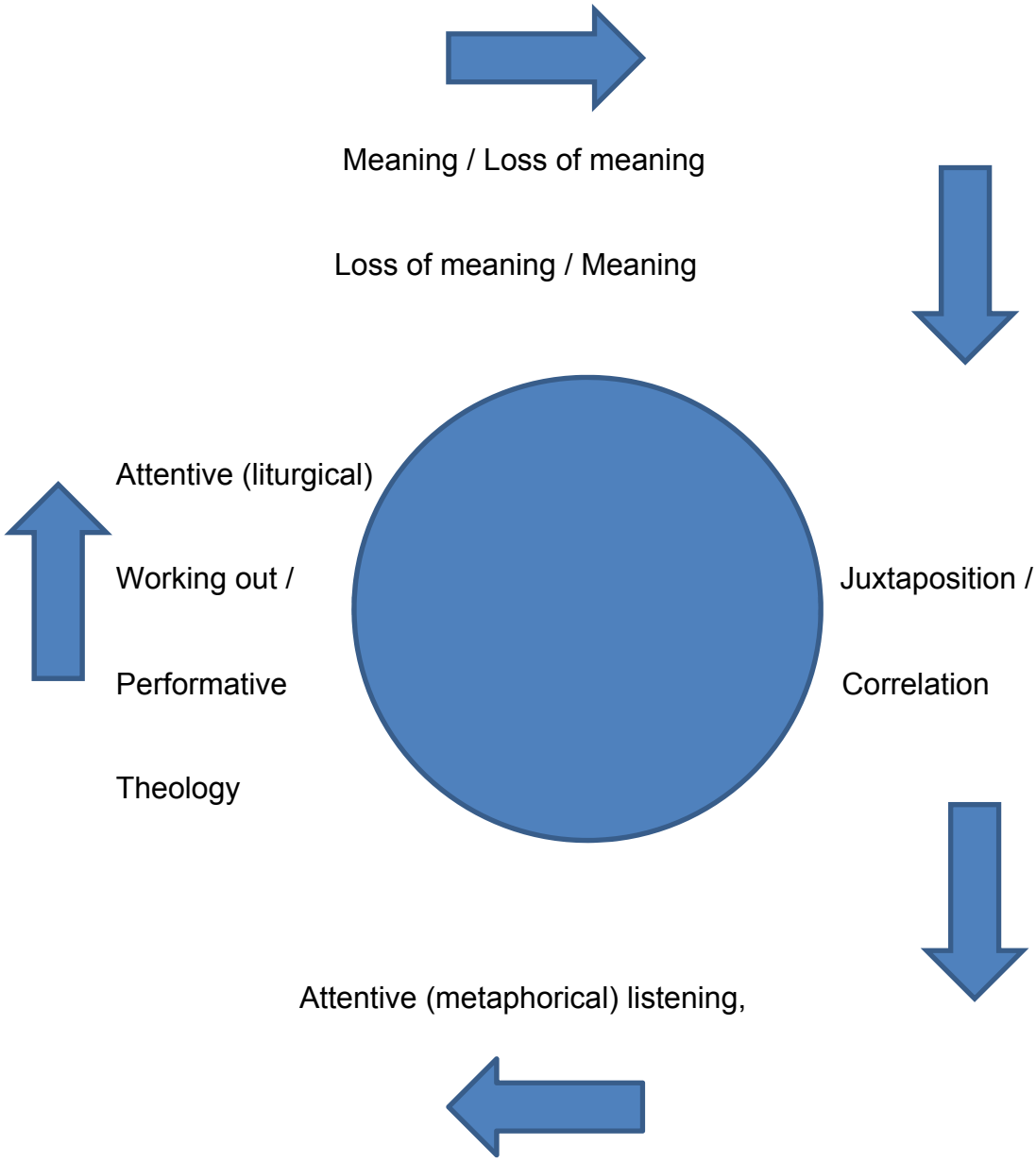
For Carr, the hermeneutical process begins when a biblical text needs not just to be read, but actively interpreted by the reader, the process of interpretation being concerned with "the dynamic interchange between text and reader" (Carr, 1997, p. 22). This interchange can proceed in one of two ways: by "putting questions to the text, as a result of which the questions are reshaped and asked anew", or "by understanding its component parts which can … only be understood by reference to the whole…" (Carr, 1997, p. 23). Either way, to "get inside the text, to become involved in the meaning" through this interactive process leads to the reader being "transformed". Scripture may contain "eternal truths", but its texts are "time-limited" and require unlocking, whether that be in an individual or group setting (Carr, 1997, p. 24, 26).

For Green, "this whole reflective exercise is best not done in isolation" as "theology is an activity of the whole body of Christ" (Green, 1990, p. 28). The process of theological reflection begins when "there is a situation that confronts us or an activity to cope with" either of which "will have the common element of worry or anguish about it" (Green, 1990, p. 25). Because "no one comes to the experience from a vacuum" we need "to explore some of our prior feelings and prejudices, for good or ill, about the experience or issue" (Green, 1990, p. 26). We then need to undertake "a thorough analysis of the situation in which it is set" using "all the disciplines at our disposal" (Green, 1990, p. 26). Then, "the situation being experienced must be brought into direct intimate contact with the Christian faith and all

that the Christian community means for us" (Green, 1990, p. 29).. Then "in the light of all the experience, exploration and reflection" the group then has to respond: "What does God now require of us?" (Green, 1990, p. 29).

The Meaning-Making Cycle combines the reflective approach of the Hermeneutical Cycle with the pastoral encounter present within the Pastoral Cycle. Preferring to regard hermeneutics as "an art" rather than "a science" (Carr, 1997, p. 23), it uses the discipline of music as an analytical tool as one of "the disciplines at our disposal" (Green, 1990, p. 26) to avoid the danger of individualizing the pastoral encounter and separating it from the wider community of faith and experience (after Green, 1990, p. 28). It roots the whole encounter within the "the dynamic interchange" of performance (Carr, 1997, p. 22). As with the Hermeneutical and Pastoral Cycles, the Meaning-Making Cycle can be understood in terms of a spiral, with each new "performance" building on, and learning from the previous one and ready to engage with the next "Loss of Meaning" episode .Thus the Meaning–Making Cycle can also be expressed in the following diagram:

Diagram 1 Meaning-Making Cycle.



In Chapter three above, having observed ten underlying themes to have emerged out of the interview material in this present research, the question remains, how do these relate to the five underlying aspects of the Meaning-Making Cycle? The table below shows the relationship between the ten core interview themes and these five underlying aspects:

Table 4 Interview Themes' relationship with the Meaning-Making Cycle.

Ten core interview themes	**Five underlying aspects**
lllness or loss leading to a reappraisal of priorities. (Theme 1)	Loss of meaning/meaning.
The unpredictability of what the future holds.(Theme 2)	Meaning/loss of meaning.
The public versus the private person. (Theme 3)	Juxtaposition and Correlation.
The context of finding out about the illness/bereavement, its present context and the effect upon the self. (Theme 4)	Juxtaposition and Correlation.
The positive and negative aspects of suffering. (Theme 5)	Juxtaposition and Correlation.
Support – faith, music and people. (Theme 6)	Liturgy, Metaphor, (Music). Attentive (metaphorical) listening.
Isolation. (Theme 7)	Meaning/loss of meaning.
The illness engendering a feeling of activity or passivity. (Theme 8)	Meaning/loss of meaning.
Coping strategy including grieving. (Theme 9)	Attentive listening
Symbols and the ownership of meaning. (Theme 10)	(Music), Metaphor, Loss of meaning, Liturgy. Performative theology.

In exploring the theologically contextualized situations of incarceration in Chapter 1 and the psychological, clinical and philosophical perspectives of Chapter 2 and Chapter 3; in the language used to reflect and discover hope in what has been experienced in Chapter 4 (which will be used in Chapter 6 to frame what will have been experienced in both in Chapter 2 and Chapter 3); the journey from loss of meaning to meaning has employed the stages of the Meaning-Making Cycle. The application of attentive listening has initiated a performative response. This present chapter will seek to explore the underlying aspects of the Meaning-Making Cycle as depicted in Diagram 1.

1 Meaning and Loss of meaning

In their definition of pastoral care, Clebsch and Jackle, see "the… sustaining… of troubled persons whose troubles arise in the context of ultimate meanings and concerns" as a key function (Clebsch and Jaekle, 1975, cited in Pattison, 1988, p. 12). As we have seen, this "trouble" can be caused by illness or loss leading to a reappraisal of one's priorities with a resulting unpredictability as to what the future holds. It can lead to extremes of activity or inactivity, all of which can be compounded if one is isolated with no one to turn to for help, but also assisted by having no distractions. How then is one to set about the process of finding meaning in one's life?

The question of whether one is able or not able to attribute meaning to one's life seems to occur either when one is experiencing a period of change in

one's life or when one is not. Shapiro and Carr believe that "Interpreting the situation afresh" is key to rediscovering meaning (Shapiro and Carr, 1991, p. 145). This is nowhere more apparent than when a person has been bereaved and the relations and functions within the family unit have to be reinterpreted in the light of the person who has died. If nothing is done and "the roles and functions previously performed by the missing member... remain unperformed" there can be no rediscovery of meaning or purpose and the family unit itself runs the risk of breaking up. (Parkes, 1996, p. 100) (Chapter 2 p. 76 - 77).

Perhaps there is no more disorganised or fragmented state than that of dementia, and therefore no greater yearning for meaning-making than those suffering from, or those watching their loved one suffering from, this illness (Chapter 2 p. 72 - 73). Yet it is possible to view dementia in a different light. Goldsmith believes very definitely that it is in the "very essence of the Christian faith that we discern the presence and activity of God in brokenness and weakness" (Goldsmith, 1998, p. 8). Bryden, is able to see dementia as a voyage of discovery, a voyage of journeying ever closer to God (Bryden, 2005, p. 161, 162).

Interpreting situations afresh in order to discern meaning in them is often inhibited if one appeals to the intellect alone, just as it would be if one appeals to the senses alone. Indeed there are times when the use of words

alone can be confusing, when one recognises the depth of an emotion but finds oneself unable to express it (Chapter 3 p. 130). Indeed one interviewee said as much: “I come to realise the inability of words to communicate the deep experiences of life” (002 p. 10). Within the area of pastoral care, Campbell is certainly aware of the limitation of words used cognitively in seeking to describe experiences in their totality. In pastoral care encounters, he believes that “we therefore need to devise an appropriate method....which appeals as much to the imagination as the intellect” (Campbell, 1981, p. 18). In rooting pastoral care in “actual human experience” his concern is “to uncover images which remind us of the transcendent dimension of this experience” (Campbell, 1981, p. 22). If one has no way of describing any given experience, one has no chance of attributing meaning to it. The use of metaphors or symbols can be extremely helpful here, a subject made all the more urgent by many previously familiar symbols and metaphors having become meaningless, and the need to re-invent symbols when they are no longer working, a subject to which I will return later in this chapter.

One of the musicians interviewed asks the question “Whose meaning is it anyway?”. Once placed in the public square, it belongs both to everybody and no-one (after 102 p. 22). But for all people, Wilson is clear that both cure and healing for example, have a social context above and beyond the individual who is unwell, cure being understood as “restoration to function *in society*”, healing as “*restoration to purposeful living in society*” (author’s italics) (Wilson, 1966, p.17, 18). Lambourne, when he says that “he only is

whole who is joined to the suffering of others", believes that healing can only lead to wholeness if society, rather than marginalising those who are ill, embraces them (Lambourne, 1963, p.162). Writing from a multicultural perspective, Lartey believes that effective pastoral care must take note of the global and cultural communities in which individuals are located, as it "requires a broad and deep engagement with living persons in their universal, cultural and unique characteristics" (Lartey, 2003, p.153). The meaning of an individual's experience is directly affected by the community or communities of which the individual feels themselves to be a part, as is the collective experience of the community by the experience of its constituent members. Meaning is transformed when health is understood holistically.

Another musician interviewee talks of how "suffering always had to be transubstantiated" and of her belief that music is an ideal medium of enabling this to happen, in which there should neither be a concentration exclusively on anger nor on that which gives joy. For her what music can help underpin, which Christianity strives to achieve, is to keep the Crucifixion and the Resurrection together (101 p. 38-41)

Keeping the Crucifixion and the Resurrection in dialogue with each other, exploring whether a variety of voices are rooted in Babel or Pentecost, is what the musical compositions examined in Chapter 4 above sought to do.

They variously juxtapose: temporality and eternity, poetry and requiem mass, accounts of desolation and biblical and prayer book texts, sameness and difference. One juxtaposes narrative and spiritual. Indeed the spirituals themselves juxtapose the journey from slavery to freedom of the Jewish people with that of African people. All of these compositions seek to explore the “wound” the “crack in the fabric” that is situated between Good Friday and Easter Day, and in so doing, give meaning to both.

2 Juxtaposition and Correlation

Central to the discipline of practical theology, and to this present study, is how disparate sources of material relate to each other, most especially traditional and contemporary material. Whilst the beginnings of correlation can be found in the theology of Thomas Aquinas which was itself “founded on the synthesis of Christian theology with Aristotelean philosophy” (Graham, Walton and Ward, 2005 p. 144), and in the nineteenth century was associated with Schleiermacher, in the mid twentieth century the correlative method was developed by Tillich, Hiltner and Tracy through whom a change can be traced in the relationship between traditional and contemporary material where the latter comes to be the ascendancy. There was also a change in the direction in which wisdom was perceived to flow: from one way to flowing in both directions. Following their example, the way forward is not to allow one or other of these aspects to dominate in the theological relationship, but, through the medium of “collage”, to nurture the energy that can be generated between them. In providing a medium for “critical dialogue”

and “theological reflection” to germinate, the opportunity is generated for “new insights” to emerge (Pattison and Lynch, 2005, p. 412, 415 – 418). Music provides such a medium as it "requires the ability to express oneself with absolute commitment and passion whilst listening carefully and sensitively to another voice which may even contradict one's own statement” (Barenboim 2008 quoted in Winkett, 2010, p. 77). As in music “the process of integration… [can be] seen as the state of the peaceful co-existence of diversity” (Boyce-Tillman, 2000, p. 245), so pastoral care needs, in the words of Frances Young, “to hold two sides of an issue in tension over and over again…to have room for a sense of complexity and mystery, even of apparent paradox” (Young, 1991, p. 235).

If in music, why not in practical theology? Is there a way of not one or other of these aspects of past and present dominating the theological relationship, but of nurturing the energy that can be generated between them in a positive rather than a negative fashion? It was noticed above (in Chapter 1 p. 30) how Bonhoeffer was helped to give a structure to his imprisonment by keeping the church's year, especially its feast days, together with singing psalms and hymns. He also set about reading the Bible, the book of Job carrying a special resonance (Bonhoeffer, 1971, p. 40). It was also noted how Moltmann, in seeking not only to understand the suffering of the present times in the light of the received tradition, also sought to say something meaningful about it. In the light of the suffering of the present times, to begin to understand this is to begin the process of getting inside the

text of the pastoral situation written on “living human documents”, to explore its dynamics of using tradition to structure the present and the present to breathe new meaning into the past.

Gill has drawn attention to the “paradox” that whilst “both religion and music depend heavily upon untranslatable symbols that tend in the modern world to be secularized, yet it is music that has also managed to retain a capacity to re-sacralize” (Gill 2010 p. 412). One cannot help but wonder whether a closer study of music can throw any light on how religion may once again rediscover the quality of 'resacralization'. How is it, for example, that disparate pieces of material relate to each other, most especially traditional and contemporaneous material? I will return to this idea later in Chapter 6 when I shall explore whether what Frank has said regarding narrative frameworks might also be applicable to musical form (Frank, 1997, p. 24).

3a Attentive Listening

If any meaning is to be deduced from any juxtaposed situations or material, it is essential that attentive listening takes place. This applies both to the person seeking meaning and any third party from whom they seek assistance in this regard. Listening attentively was a major feature of the client centred therapeutic approach pioneered by Carl Rogers during the 1940s. Undergirding this approach was the quality of the relationship that the counsellor established with the client. It was also a central feature of Lake's

“Clinical Theology” for whom, because he believed that "God has not only spoken through his Son, ... he has listened through his Son", listening was an activity that came with a divine imperative (Lake, 1966, p. 11). Listening to a person, especially a patient or a bereaved person, gives them permission to tell their story. In so doing, Frank believes, it enables them to turn “the dominant cultural conception of illness away from passivity…toward activity”, it “transforms (their) fate into experience” (Frank, 1997, p. xi). He advocates that patients “need to become story tellers in order to recover the voices that illness and its treatment often take away” (Frank, 1997, p. xii). Recovering their voices has an effect on those who hear them, “as story tellers, they care for others” inviting others to share *their* stories, *their* particular “conditions of embodiment” (Frank, 1997, p. xii, 25). Listening to what the whole person is saying leads to what Swinton describes as nothing less than the “resurrection of the person” (Swinton, 2000, p. 10).

Attentive listening would seem to be key to those seeking to cope with life changing experiences especially when that involves grieving over a loved one's death. As isolation and loneliness are so often concomitants of change, whilst some people need their own space, others, when they became aware of what had happened to them and what was being done for them, were grateful that so much attention was being given to them. This was apparent to me when I conducted the interviews. One interviewee needed to listen to himself and so wrote a day to day diary on his experiences (202 p. 9). On the other hand one interviewee needed others to

listen to his normality, others to their humour (206 p. 6). Listening attentively to the needs of children who were grieving at the death of their teacher enabled the establishment of a quiet room where the children could go when they were feeling upset. There they could produce beautiful pieces of work that were put up on the wall (002 p. 8). The telling of personal stories clearly has a re-creative function. Frank's remarks concerning illness are equally applicable to the bereaved. "Stories have to *repair* the damage that illness (or bereavement) has done to the ill (/ bereaved) person's sense of where she (/he) is in life and where she (/ he) may be going." (Frank, 1997, p. 53) Attentive listening is nothing less than loving courtesy.

In the course of this research, one of the musicians (the conductor) interviewed made a startling claim about listening. He said, "I have two rules... 'Tell the truth' ... and 'Listen'. They are one and the same really." (103 p. 11) In the course of an orchestral rehearsal, one cannot prepare authentically for a performance unless one seeks constantly to improve the standard of the playing (or singing) of the musicians one is conducting. This critical listening is not just being undertaken by the conductor but by the musicians themselves. Both have a standard of intonation, rhythmic and dynamic accuracy to which they aspire. Yet interestingly this same interviewee recognised that it is not for the conductor to impose his/her will on musical colleagues. Rather they have to be invited with you into this performance. Concerning the overall vision of a musical composition, "you mustn't go out there and try to suggest that you have some great

interpretation...you just need to do it right and then it comes across" (103 p. 13-14). The net result of this process on the performers can then be that "You lifted them into a place that they didn't know they were going to go to." (103 p. 27) He offers himself, and other music makers, the practical advice, "Before you do something, think." (103 p. 18) Yet paradoxically, he also mentions that too much listening can get in the way of music making. To conduct a musical performance successfully, "I'm not really listening. Because if I'm listening I'm not moving forward...You have to live in the present." (103 p. 25) For the hospital chaplain, this can be a timely reminder of listening in such a way that one is not overwhelmed by what one is being told.

But music *making* is only half of the equation. There is also the role of the audience to consider; there is no point in creating and recreating music unless it is also accompanied by "music *hearing*". Similarly in the pastoral relationship, there is no point in talking and sharing one's concerns if there is nobody to listen to them and offer some kind of response (Begbie, 2000, p. 28). "The Wounded Story Teller" (Frank, 1997, p. xi) is complemented by the wounded listener who, by the act of listening, becomes in effect "the Wounded Healer" (Nouwen,1994, p. 81). The context in which musicians perform and an audience listens can affect the way that the music is interpreted. Messiaen always maintained that he had "never...been listened to with such consideration and understanding" as he had in that prison camp

(Golea, 1960, p. 63 cited in Pople, 1998, p. 16). As Frank reminds us, “In listening for the other, we listen for ourselves” (Frank, 1997, p. 25).

3b Metaphor (Attentive metaphorical Listening)

We saw above how attentive listening requires not just “listening to what *is* being said but also to what *is not* being said”. Because “sometimes the difficulty of recounting painful experiences is born of an inability to attribute meaning to them”, symbols and metaphors can be a way of engaging with an experience, particularly when it has been, in the word of one interviewee, “ a surprise... a bit of a shock...a bolt from the blue” (204 p. 9). Sometimes metaphorical language can help (see McFague, 1983, p.15). At other times, the use of symbols can be of assistance (see Williams, 1983 p. 283). As has been seen, both liturgy and music exercise symbolic functions that will be considered in more detail below. Of particular interest in this research study is the ability of symbols and metaphors to help individuals unlock, become involved with, and own the meaning of the situations and texts with which they engage.

If the importance of metaphor and symbols is acknowledged, so too is the need, when they have become redundant, to interpret them afresh (Eiseland, 1994, p.95).Tillich agrees, arguing that whilst “Images have become symbols which participate in the reality to which they point,” symbols also “grow and die “ and so constantly have to be reinvented (Tillich, 1957 and 1973, quoted

in Campbell, 1981, p. 20). Farley believes that “we live in a society puzzled about itself” (Farley, 1996, p. ix). Part of this he puts down to a loss of significant symbols, without which, “a society becomes alienated from past wisdom, develops institutions that have little connection with sources of humanization and instigates styles of everyday life whose primary function is ephemeral entertainment and trivial comforts” (Farley, 1996, p. ix -x).

Sometimes, it is the metaphors themselves that provide a source of stability within a world that appears to be in a great state of flux, if you are not to avoid the situation. To use one interviewee's metaphor: "once you're kind of on the roller coaster you have to just keep going until you get to the end” (102 p. 27). A further interviewee, acknowledging the need for some kind of stability in the midst of the chaos, felt that it was important “...to know that ... there are a number of fixed points that you can tie your rope to” (204 p. 13). Sometimes it is symbols that provide stability.

As well as a way of communicating better and understanding one another within the pastoral setting, this approach can also benefit our understanding of written material. In advocating the use of the intuitive over and above the rational function of the brain when looking at a Biblical text, Lyall believes that Breugggemann's approach and his "use and development of the imagination (which) becomes a primary way of knowing" can be extremely productive (Lyall, 2001, p. 82). Lyall believes that the metaphorical nature of

parables has much to tell us in this respect as they can be regarded as "stories about ordinary things with the power to disclose the nature of reality"(Lyall, 1995, p. 13). This is why McFague refers to them as “parables of the kingdom” (McFague, !983, p. 14). Furthermore, "it is not simply that the pastoral *conversation* must be interpreted metaphorically and parabolically, but also the pastoral *relationship* has a parabolic character through which the Grace of God shines through" (my italics) (Lyall, 1995, p. 13).

Music can operate metaphorically by unlocking, and thereby discerning, the meaning of a situation, and can be a bridge to past memories and act as an anointer or a healer of wounds. One interviewee bears testimony to this by telling of a friend who “wrote an incredible song... about his father who had abused him.” She describes such a song as a Lorica (meaning a breastplate) (101 p. 17). “The song distances you from the emotions...It’s a holding form and once they're held in some form they are more manageable” (103 p. 20).

But music can also draw attention to pain and suffering (caused by the dichotomy between what should be and what is) when enfleshing the reality that “the sound is an audible scar of damaged tissue underneath”, (Winkett, 2010, p. 5). As was noted above (in Chapter 4 p. 138-145), in music, one way that this scar or wound can be represented is through dissonance. But

just as a wound can be represented through dissonance, so musical healing can be represented through consonance. This was the position adopted by Boyce-Tillman in “Space for Peace” in which, out of her five additional chants, four use the pentatonic scale in which there are no semitones, thus establishing a sense of consonance. (And in the additional chant which does use semitones, these represent more of an embellishment that can be contained rather than major dissension which cannot.) However, McFague is right when she says “*moving beyond* metaphors (and we might also add, symbols) is necessary both to avoid literalizing them and to avoid significant interpretations of them for our own time” (author’s italics) (McFague, 1983, p.22 – 23) . Each generation needs to discover afresh its own metaphors and symbols.

4 Liturgy (Attentive liturgical Working out) and Perfomative Theology

Liturgy provides one particular way of exercising symbolic and metaphorical functions. It does this by enabling individuals, and the communities of which they are a part to engage, unlock, become involved with, and to own the meaning of the situations and texts with which they come into contact; in other words engage in performative pastoral care. This is possible because liturgy (in exerting ‘Lorica’ qualities of its own) provides a medium for holding in a safe place that which is almost too hard to bear and offers out the hope of transforming it. Shapiro and Carr refer to this as a “holding environment” which provides “empathic interpretation and tolerance and containment” in which difficult feelings “can be addressed through ritualistic symbolic

structure that enables chaotic experiences to be faced" (Shapiro and Carr, 1991, p. 160). An act of worship can thus be a symbolic "holding environment" within which the "transitions of life" can be affirmed and worked through, articulating feelings of sadness as well as celebration (Shapiro and Carr, 1991, p. 36). Part of the process of engaging in performative pastoral care rooted in a faith tradition is to reflect theologically upon a given historical or contemporaneous situation or text, and in so doing offer an interpretation which can either be accepted or rejected.

Sometimes liturgy (both religious and secular) serves the function that was observed in the previous section, of enabling those attending "...to know that ... there are a number of fixed points that you can tie your rope to" (204 p. 12). Chants and drones serve as a kind of "umbilical cord" to the sacred (Begbie, 2000, p. 136). For some this will be hearing favourite passages of scripture or singing favourite hymns (p. 110). For one interviewee who was ordained and couldn't get to an act of worship himself, or for another who simply couldn't pray (002, p. 3-4), it was being sustained vicariously by the community of faith. On those occasions when the former was well enough to celebrate the eucharist, this liturgical act enabled him to "maintain… the priestly life". Being sustained by liturgy at which he was physically not present, but particularly when he was, enabled him to take "the spiritual winter with me, into that spiritual summer" (001 p. 10). It is as though, as one of the interviewee's observed of music, liturgy too, by its very existence in sound in the present moment, affirms that we not alone (after 103 p. 29).

As well as providing an ""umbilical cord" to the sacred", liturgy also can act as a bridge to past memories. Sometimes it will serve as a healer of wounds. Sometimes, however, as was noted in the War Requiem, no unlocking occurs through the words of the requiem mass as there is the perception that ritual itself (or more specifically church ritual) is also dead. This in turn leads back to a sense that the ritual itself, and the liturgy contained within it, has to change. Just as music itself can be understood as a kind of performative theology, I would go further, to maintain that liturgy and pastoral care are inextricably connected, the former being the outworking and response to the latter. This applied irrespective of whether the liturgy is religious or secular (as a rite of passage in nature) or is worked out in the public or private space (including the pastoral care relationship itself).

Clearly there is a very close connection between liturgy and music. The fact of being involved in liturgy can of itself be therapeutic and transformative. It can be redemptive. If the liturgy is seeking to process a painful experience, it can enable one to sense the numinous, the place of the crack being the place of the greatest beauty (after 101 p. 33). In the War Requiem for example, it was noted above how the Sanctus and Benedictus are messages of serene joy, even in a mass for the dead (Evans, 1979, p. 460). Sometimes a liturgy at which one is present, like listening to music, can conjure up a particular mood, which can find release in the remembrance of previous

liturgies. Liturgy, like music, can bring a sense of structure to chaotic personal experiences and can provide the framework in which a person can tell their story (Frank, 1997, p.24). It can lift the spirit, but sometimes, it can have quite the reverse effect as internal pain is released and tears can flow, in which case liturgy can prove liberative. Young has said that “Story making is a step on the road to abstract analysis and story telling the most effective way of communicating collective experience and values” (Young, 1991, p. 2). Perhaps liturgy, like music, is essential, because it facilitates both “story making” and “story telling”, the very building blocks of performative theology, and if people are not able to enter into it, that is an indication that “something has gone out in their life” (103 p. 29). That is nothing less than the ability to be open to the possibility of re-appraising ones priorities, to be open to the possibility of meaning-making.

Conclusion

This chapter has sought to suggest some possible signposts on the journey from loss of meaning to meaning-making for those who experience periods of profound darkness in their lives. Drawing upon insights from the Hermeneutical and Pastoral Cycles (Carr, 1997, p. 23; Green, 1990, p. 25 - 30), I have suggested an expanded approach which I have expressed in the form of a Meaning-Making Cycle which seeks to discover wisdom emerging out of lament. The juxtaposition of opposing world views whilst initially exacerbating loss of meaning, can also begin a reaction arising out of these opposing views that can lead to a change of perception and a new sense of

meaning becoming established once again. This chapter has suggested that implementing this process requires not just attentive listening to what *is* being said but also to what *is not* being said, and what is being said metaphorically; and it requires a response which needs some kind of attentive performative working out.

The Meaning-Making Cycle differs from the Hermeneutical and Pastoral Cycles in that, drawing upon the world of music making, it incorporates listening and performing. These two activities of listening and performing, reflecting and acting, are intricately bound together, but because they lead to change, (like the Hermeneutical, and Pastoral Cycles) the Meaning-Making Cycle is not strictly circular but more like a spiral (Green, 1990, p. 25). Just as perfect meaning-making, like the perfect performance, is never achievable, the pastoral encounter can be understood as being comparable with the act of music making itself.

Chapter 6.

A new form for Pastoral Care

Introduction

In tracing a journey that seeks to travel from loss of meaning to meaning-making, the last chapter has explored how the various aspects of the Meaning-making Cycle (most importantly incorporating listening and performing) can be seen to underpin, not only the general situations, perspectives and frameworks that have been examined in this dissertation, but also variously the themes that have emerged out of the interview material. A comparison has been suggested between the pastoral encounter and the giving of, and listening to, a musical performance. In order to bring new understanding to the pastoral encounter, let us explore the possible connections.

1 Musical form as a possible model for pastoral engagement

In talking of the function of artists, John Paul II talks of it being the artist's vocation to “search for new 'epiphanies' of beauty” (John Paul II, 1999, quoted in MacMillan, 2008, p. 12). Can pastoral care offer epiphanies of beauty, the hope that 'nothing (and no-one) is unredeemable? A number of definitions of pastoral care variously talk of:

“helping acts...directed towards the healing, sustaining, guiding, (nurturing) and reconciling of troubled persons whose troubles arise in the context of ultimate meaning and concerns” (Clebsch and Jaekle, 1975 cited in Pattison 1988, p. 12);

"the elimination of sin and sorrow and the presentation of all people perfect in Christ to God” (Pattison 1988, p. 13);

"the establishment of a relationship or relationships whose purpose may encompass support in a time of trouble and personal and spiritual growth through deeper understanding of oneself, other and /or God" (Lyall, 2001, p. 12).

But that which speaks most directly to the loving nature of the pastoral relationship itself, is that of Campbell. "Pastoral care is in essence surprisingly simple. it has one fundamental aim to know love, both as something to be received and something to give" (Campbell, 1985) (cited in Pattison, 1988, p. 16).

Within the context of pastoral care, “’epiphanies’ of beauty” are greatly enhanced when an identifiable relationship exists between those giving and those receiving pastoral care (whether it be long lasting or recently established), when a mechanism is found for helping people let go of that which burdens them enabling spiritual growth to take place. The loving quality of the relationship is essential.

Music provides a timely reminder of those aspects which are essential to effective pastoral care. As those interviewed have born witness, in giving the space in which the potential for healing and wholeness exists as a possibility, through attentive listening, pastoral care must provide a safe place in which people can give voice to that part of their story which they wish to tell. Both the telling of, and the listening to, this story is dynamic, performative and creative. In providing an environment in which “God's being-ness”, can break through “humanity's doing-ness”, it offers the hope of moving through periods of darkness (see p. 148 -153 above). If this is so of pastoral care in general, what of specific models of pastoral care?

In order to arrive at some suggested models of care, this chapter will begin by considering whether specific examples of musical form (the simplest of which, as was noted in Chapter 5 in connection with the Meaning-making Cycle, is collage) can provide helpful models for pastoral engagement (Appendix 2). It will explore whether, as Frank has said of story, *musical* “Frameworks can disentangle types of narratives; they can help in recognizing what basic life concerns are being addressed and how the story proclaims a certain relation of the body to the world” (Frank, 1997, p. 24). In essence, musical form lays bare music’s structure, revealing how contrasting and similar material is “collaged” in such a way that a new work of art is the result. It offers the possibility to pastoral care that contrasting wisdoms born of received traditions of faith and contemporary experience rather than appearing to negate each other, through “critical dialogue” and “theological

reflection", offer "new insights" to both (Pattison and Lynch, 2005, p. 412, 415 – 418). I have chosen to use examples from the world of music. Others might equally well chose formal examples from architecture, the visual arts or drama. The principle remains the same, to use other frames of reference better to understand, inform and find ways of relating to, theological praxis. In seeking to investigate whether specific musical forms can be helpful models for pastoral engagement, some of those outlined in Appendix 2 will be applied to the case studies and interviewees considered earlier. The particular forms which this study considers helpful in processing pastoral encounters can be represented by the following table:

Table 5 Case Studies/Interviews categorised by Musical Forms.

	Monothematic Forms	**Case studies/Interviews**
1	*Fantasia*	*(103)*
2	*Theme and Variations*	*(003),(203)*
3	*Fugue*	*Case study 5, (001)*
	Dualistic Forms	**Case studies/Interviews**
4	*AB (Strophic)*	*Case study 2, (201)*
5	*ABA (Da Capo)*	*Case study 1 , Case study 4, (002), (202), (204), (206)*
6	*Rondo*	*(102), (205)*
7	*Sonata Form*	*(101), Case study 3*

Thus from this table it will be seen that there are slightly more than two and a half times as many examples of pastoral encounters represented by Dualistic

forms, (thirteen examples) than were represented by Monothematic forms (five examples). A possible reason for this might be that in seeking to relate the present moment with what has gone before and what will follow, in the pastoral encounter, 'difference' is far more likely to be the default position than 'sameness'.

Monothematic forms

Fantasia

Interviewee 103 was the only musician interviewee who did not share much about experiences of darkness that had occurred (if indeed any) during his life. Because of this, the interview proved very difficult to frame within a musical form. The only form which suggested itself was that of **Fantasia**, because of the improvisatory nature of his conversation concerning his musical life which continues to unfold

Theme and variations

The interview with interviewee 003, the Leader in Public Life who had had bowel cancer, can be compared to a **Theme and Variations** with her illness being likened to the theme (stated in a minor key), and the various ways the illness plays out in the differing facets of her life as the variations. Because she is now in remission, the way she now looks upon her illness could be compared with the final statement of the theme that has been transformed in

some way (as in Rachmaninov Paganini Variations in which, towards the end, the theme, which initially appears in a minor key, is inverted and appears in its major form).

The interview with the patient with the life-threatening bronchial pneumonia which led to a marked memory loss, interviewee 203, also fits within the framework of a **Theme and variations** with the patient's faith being the Theme, and the various ways her constant faith sustained her through her illness, being the variations.

Fugue

Case study 5, concerning the patient with Dementia (R2), can be compared to a **Fugue,** the patient's ever present dementia providing the fugal material, with his brief, but diminishing, periods of clarity, such as engaging (however briefly) with past memories and with the outside world, the episodic material.

The interview with interviewee 001, another Leader in Public Life (now deceased) who had suffered from Leukemia, could be framed in a **Double fugue**, with the patient's support derived from his faith, family and friends constituting the first fugal material group, with his illness, the second fugal material group. In this example, the episodic material is represented by alternating periods of illness and wellness in varying degrees.

Dualistic forms

Strophic (AB) Form

Case study 2 concerning an eight year old girl who died on the Children's Ward (C), can be compared to the **Strophic (AB) Form** in which the patient's death and bereavement of her family is represented by letter A, and the children's memorial service which grew out of it enabled others to grieve over the loss of their children who had died by letter B

Interviewee 201, the patient with Kidney failure leading to dialysis, can also be compared to the **Strophic (AB) Form** in which the patient before diagnosis and the beginning of dialysis is letter A and the patient now that his dialysis is regularly under way, letter B.

Da Capo (ABA) Form

Case study 1 about the middle aged male patient, diagnosed with the life limiting illness of Motor Neurone Disease (T), can be compared to the **Da Capo (ABA) Form**. In this example, the patient's positive attitude to life (and his determination to have the last laugh) is represented by A; the illness and his subsequent death by B; the patient's positive attitude to life (and his determination to have the last laugh by a third party reading out the homily that he had written for his funeral) again represented by A.

Interviewee 206, the patient with breast cancer leading to chemotherapy and double mastectomy, also follows this **Da Capo ABA Form**. The patient's

wellness (or relative wellness) can be seen as A; her diagnosis, chemotherapy and double mastectomy as B; her wellness (or relative wellness) returning once again to A.

Case study 4 of the man with a profound learning disability (R1) also fits an extended **Da Capo (A1BA2) Form** where R1 when alive is represented by A1, his death and the making of funeral arrangements by B, with the staff's recollections of R1, of whom they were clearly very fond A2. (In musical terms, it feels as though A1 would be in a minor key and A2 in its relative major key.)

Interviewee 002, the Leader in Public Life whose wife died through breast cancer, follows the same extended **Da Capo (A1BA2) Form**. Following his wife's diagnosis and deteriorating condition, her experience within mainstream healthcare and hospice can be seen as A1; her terminal phase and her death as B; his remarriage and the establishing of new family dynamics as A2

The interview with the patient whose diabetes led to a partial amputation of one of his legs, interviewee 202, also matches this **Da Capo (A1BA2) Form**. The patient's deteriorating leg condition can be seen as A1; his amputation B; his recovery and rehabilitation A2.

The final example of an interview fitting within this modified **Da Capo (A1BA2) Form** is that of patient 204 who had experienced a heart attack resulting in memory loss. Here the patient's faith is A1, his heart attack and

memory loss B, whilst the processing of his faith in the light of the heart attack A2.

Rondo

Interviewee 102, the musician who experienced the death of her father when she was still a teenager can be portrayed in this **Rondo** form. Her beginning to compose can be represented by letter A; the death of her father by B; her composing in response to her bereavement by A; the death by suicide of a friend by letter C; her composing in response to her bereavement by A; her broken relationship by D; her composing in response to the difficulties of her life again represented by letter A.

Interviewee 205, the patient with the hip replacement which then became infected leading to readmission, fits within an extended **Bridge Rondo** (so called because if the B sections are joined together by a curved line, they form an arch structure around the central C section). In this form, the patient waiting (for her hip operation) is A; her recovering from her operation B; her waiting (to go home) A; her contracting an infection C; her waiting (for her infection to recede so that she can have another operation) A; her recovering from her second operation B: her waiting (to be discharged) A.

Sonata Form

The interview with the musician who had suffered with clinical depression, interviewee 101, matches the pattern of **Sonata Form**. In this encounter, in the Exposition, her grounding in academic music and Christian theology can be represented as being the first theme, whilst her interest in folk music and folk spirituality as the second theme. Her continual engagement in tension caused between these two themes which sometimes manifests itself in periods of mental illness can be compared to the Development section. The Recapitulation is that section in which the interviewee continues to find her own voice in the process of engaging with these two original themes.

Case study 3 concerning the active female patient in her sixties facing amputation (S) fits within an extended **Bridge Sonata Form** (so called because if the first and second themes in the Exposition and their counterparts in the Recapitulation are respectively joined together by a curved line, they form an arch structure around the central Development section). In the Exposition, the importance of the patient's body image (over life) and her not wanting the operation is represented by the first theme, whilst the importance of her life (over body image) and family and doctors wanting her to have the operation by the second theme. The engagement in this argument which reaches its climax with the amputation occurring then constitutes the Development section. In the Recapitulation, the importance of her life (over her body image) having now become justified is the second theme, with the patient preferring to have died than having had her body mutilated, the first theme.

Whilst considering whether specific examples of musical form can provide helpful models for pastoral engagement, it is very important to remember, that these engagements remain pastoral encounters and never become staged performances. The choice of which form to apply to which pastoral situation is, and has inevitably to be, a personal application. A different researcher might find different forms more applicable. For example, those suffering with a continual or returning illness could be portrayed by using the form of the Ground Bass or Passacaglia, or as Michael Mayne has done in talking about his own illness, Cantus Firmus (Mayne, 2006, p. xviii). That which is important is not the particular forms used, but that specific musical forms can be helpful in framing, and thereby processing pastoral encounters. But what of the players in the pastoral care encounter, the 'performer' and the listener? Can music help here too?

2 Musical function as a possible model for pastoral caring

Stevenson-Messner's use of the metaphor of music on the wider theological stage in her transposition of Anton Boisen's 'living human documents" into "living human instruments", develops the image of practical theology as orchestra. For her, practical theology is an orchestra which is concerned with harmonious relationships with other 'musicians' (those practitioners of various theological disciplines and those caught up in the organisation of parish life), not appearing "as soloist or guest musician" but playing "in

concert" with them, with, most importantly for this present discussion, the minister as the conductor (Stevenson-Moessner, 2008, p. 1.) Sometimes this engagement can be discordant and cacophanous, but "cacophany precedes harmony and creation" (Stevenson-Moessner, 2008, p. x). For her, in this metaphor, “theology is the music of religious enquiry” (Stevenson-Moessner, 2008, p. 1). Thus practical theology is a spiritual symphony that collages faith and action, putting faith into action and action into faith. It offers connectedness not only to other disciplines but to each other (Stevenson-Moessner, 2008, p. 69). Just as the minister is seen as the link between the “various theological disciplines” and present pastoral engagement, so the healthcare chaplain can be a link between non theological professional healthcare staff and the pastoral encounter.

Frances Young drew a parallel between performance and hermeneutics, (by way of broadening the question concerning the authority of scripture thrown up by the application of literary criticism to its texts), by asking “How can we perform the Bible – in a modern world so different from the past which produced and used it?” (Young, 1990, p. 1). Whence lies its inspiration? Influenced by Koestler, Young believes that there is a kind of inspiration which is born “of previously unrelated frames of reference or universes of discourse – whose union will solve the previously insoluble problem” (Koestler, 1964 cited in Young, 1990, p. 2). Meaning, as does inspiration, lies beyond perceived contradictions between texts, and beyond those between traditions of faith and current experiences.

David Lyall, in effect, asks a similar question of pastoral care, as Young asks of hermeneutics above. How can we perform pastoral care – in a modern world so different from the past? He understands pastoral care to be “a creative art” which similarly is able “to tolerate ambiguity and ambivalence…that awakens the imagination and evokes awareness of new possibilities” (Lyall, 2000, p. 311). One response to this is modeling pastoral care following the pattern of musical improvisation. But, as Lyall continues, “Sometimes situations are of such ethical complexity that there is no obvious right thing to do; sometimes life is so tragic that there is nothing to be said which will ‘make things better’.” (Lyall, 2000, p. 311) But even in simply being there, “the toleration of ignorance (of itself) becomes an enabling grace” (Lyall, 2000, p. 317). Then, as in hermeneutics, so too in pastoral care, “only in the empty space created by God can a resolution of human strife be played out. Only in the empty space that *is* God can the drama be truly holy and the invisible be made visible” (author’s italics) (Young, 1990, p.191).

Stevenson-Messner's idea of "living human instruments" hints that music might have something to offer the players in the pastoral care encounter, as what can be true of the macrocosm, can also be true for the microcosm (Stevenson-Moessner, 2008, p. xiii). One of the musicians interviewed talked of how in one of the choirs he conducted, a choir member had a disabled daughter who “wrote me a poem... which was called Jesus Christ the conductor” (103 p. 28). Stevenson-Moessner, in seeing “the theological,

christological, import of the position of conductor", believes that "God or Christ may be seen as a unique realisation of this creative co-ordinator, the conductor". But she understands the conductor as performing a "non-hierarchical role" thereby seeing it as a helpful "model for practical theological leadership" (Stevenson-Moessner, 2008, p. 54). If Christ is understood as a conductor, so much more so must be his ministers. If the minister (chaplain) is seen as conductor, and the role of the conductor is, as Hunter asserts, "to "orchestrate", read and understand the music, know its history and its meanings, give attention to nuances and subtleties and enable the playing by the orchestra of a great symphony" (Hunter, 2004, p. 128 cited in Stevenson-Moessner, 2008, p. 54); then the chaplain has to illustrate the qualities of "involved detachment and critical responsibility" (Woodward, 2000, p. 17). In describing conducting as involving "listening" and "truth-telling", but truth telling that is "encouraging", the above interviewee emphasises just how important that "involvement" is (103 p. 11).

But there are other musical functions that can also bring clarity to the nature of the pastoral relationship in which chaplains are involved. Chaplains can be compared to the space in which music is performed. The work of chaplaincy itself takes place in the large performing space of public liturgy and various health care committee meetings, and the smaller space of bedside ministry. As the spiritual performing space, the chaplain provides for the patient a safe place in which unrecognised feelings can be recovered and then rehearsed, where "immersion in the wounded scar of damaged tissue can

take place, out of which healing comes and to which it goes" (Boyce-Tillman, 2000, p. 282). The chaplain offers a place where people can tell their stories, and by doing so, gives permission for people to do so, so that they may let go of their demons, and in the telling of those stories find healing, and learn to play (perform) once again. In doing this, chaplains are simply following the pattern of Jesus' disciples who, by telling their story, invite us to enable others to tell their story.

If chaplains are to act as effective auditors, they must themselves be connected to something of the numinous and enable others to do likewise. This enables them to maintain " a religiously distinctive and critical standpoint in health care chaplaincy and spirituality" (Pattison 2001 p. 39). They must pay attention to the person who is performing, by providing a relational bridge through which a person may articulate their innermost redemptive desires. In the act of listening to another's stories, the chaplain must strive to discern God's presence within them. To be effective pastoral carers, as well as being effective auditors, chaplains must also be drawn into performance themselves, responding to the cries arising out of the pastoral encounter and those arising from the tradition of faith, the one empowering the other, and God being in them both; ensuring that a continual dialogue must inevitably take place between them. The patient's performance, their "cry of the heart", is nothing less than a demand for wisdom, a demand for understanding amidst that chaos of living (Ford, 2007, p. 5). Because of the chaplain who truly listens, the patient is able to articulate that his or her performance is "not

a *flight from* the world of pain and matter but a *mission into* it" (author's italics) (Vanier, 2004, p. 13).

Through the chaplain's attentiveness, affirmation is given to patients who are encouraged to believe, and apply to themselves, that the central tenet of the human condition is to accept and love oneself. This reflects Tillich's perception of being able to accept that one is acceptable despite appearing unacceptable alluded to earlier in this study (Tillich, 1952, p. 147 - 148) (Chapter 1 p. 35-36). Both music and pastoral care exist within the present moment, the relationship between teller (performer) and hearer (listener) continually coming alive in each successive present moment.

Conclusion

This chapter has continued to look at whether pastoral care has any lessons to learn from the world of music. In an attempt to explore a new method of pastoral discernment, communication and enablement, it has considered whether musical form might be a helpful tool with which the healthcare chaplain might begin to process pastoral engagement. In moving towards a new model of pastoral care it has considered whether musical function might be seen as a model for pastoral caring. Finally it has explored the model of chaplain as conductor, concert hall / chamber music salon and audience; and of the chaplain and the patient caught up in the co-equal performance of a duet. The following chapter explores whether the above has anything

helpful to offer by way of recommendations pertaining to the pastoral practice of healthcare chaplaincy within a multi-disciplinary setting which is increasingly secular.

Chapter 7

Recommendations for Pastoral Practice

Introduction

This dissertation has sought to investigate the kinds of language and metaphor used by people who are experiencing times of existential difficulty in hospital. It has set these alongside the kinds of language and metaphor used in a selection of other situations in which people have experienced episodes of metaphysical darkness. First hand experiences have been gathered through interviews with a purposive sample of people (Chapter 3). This study has revealed journeys of meaning-making that discover a wisdom rooted in lament. It has incorporated "reflection upon lived contemporary experience", engaged in "critical dialogue between theological norms and contemporary experience", employed, through the use of music as a dialogue partner, "an interdisciplinary approach", and revealed "the need for theoretical and practical transformation" within healthcare chaplaincy (Pattison and Lynch, 2005, p. 410 – 411). It has specifically drawn upon the world of music. It has suggested musical *form* as a way of framing pastoral encounters and musical *performance* as a way of better understanding the dynamics contained within the pastoral encounter itself. In using the device of "Collage" (as it is presented through the medium of music) to describe a creative process in which various, often contrasting, materials are juxtaposed to form a new composition, it has employed a model of theology in which "critical dialogue" and "theological reflection" merge to generate "new

insights" (Pattison and Lynch, 2005, p. 412, 415 – 418). My hypothesis has been that, within the hospital setting, if the chaplain can have a clearer picture of how pastoral encounters function, it will add value to the provision of pastoral care in the health care environment. This will in turn have a considerable influence on patients' articulation of their pastoral and spiritual needs.

However, it is very clear that those grounded in a secular, faith-neutral perspective have a different view of chaplaincy to those from a religious faith-specific perspective. Miranda Threlfall-Holmes has observed that context is key in determining the shape of models of chaplaincy and may lead to a mismatch of expectations. The list includes:

Table 6 Theological and Secular models of Chaplaincy (Threlfall-Holmes, 2011, p. 116ff).

Theological models	**Secular models**
1 Missionary	6 Provider of pastoral care
2 Pastor	7 Spiritual carer
3 Incarnational / Sacramental	8 Diversity
4 Historical i.e. parish	9 Tradition / heritage
5 Cluster of models as agents for challenge / change	10 Meta Model / Specialist service provider

It would be strange if a Christian faith-based healthcare chaplain did not identify with the theological models rather than the secular models of chaplaincy. Applying the above model has implications for chaplaincy as shown in Box 1.

Box 1 Application of Table 6 to health care chaplaincy (numbers refer to items in Table 6).

The chaplain's role *is:*

"to bring the gospel to the people there (in hospital) in whatever ways may suit the context" [1];

"to care for people…unconditionally and without demanding any response"; [2]

to be "inspired by the being and nature of Jesus rather than (just by) his actions" [3];

to be "present and engaged with the whole life of the place (the hospital)" [4];

to be "challenging the status quo and speaking prophetically to unjust structures" [5].

In executing this role, the chaplain *will* be expected:

to "be able to assess need and create care plans to meet that need"; [7]

to provide "professional advice in the area of diversity" [8];

to be "a provider of specialist support services" [10].

The chaplain *may* also be expected:

to "provide 'civic' services" [9].

If chaplains are to remain true to the guiding principles undergirding the theological models of care, their role can only be undertaken effectively and with integrity (and, most importantly, viewed so by their employing organisation) by their building up and continually nurturing meaningful relationships with the patients and staff. In this way,

The chaplain *will* be*:*

"valued for the pastoral care given" especially "at times of crisis". [6]

The chaplain is perhaps the ultimate example of collage, when engaging in "critical dialogue between theological norms and contemporary (secular) experience" generates "new insights" through perfomative theology (Pattison and Lynch, 2005, p. 410, 411 – 418). Through engagement in such a process throughout this thesis I believe it is now possible to frame recommendations pertaining to improving the pastoral practice of hospital chaplains.

Recommendations for Pastoral Interventions arising from this study

Throughout the course of this thesis, ten core interview themes (Table 2, p. 89) and five underlying aspects (Table 4, p. 161) were observed, each of which have implications for healthcare chaplains' pastoral praxis. I would like to focus on three of these namely: Attentive Listening; the Public and the Private Person; and Symbols and the Facilitation of Meaning.

1. **Attentive Listening** – *modelling the presence of God*

Chaplains must be proactive in rediscovering what it means to really listen to another person. To make this point might at first seem something of an oxymoron as listening is so key to the pastoral task. Attentive listening is particularly crucial in Carl Rogers' psychological approach of the 1940s and in Lake's Clinical Theology of the 1960s and 1970s. This kind of listening is particularly important for those trying to process life changing experiences especially when that involves grieving over a loved one's death, attentive listening being nothing less than "loving courtesy" (p. 170). Insights from music make clear that as well as being attentive, listening must be reflective and thus occasionally critical, because it is about nothing less than truth telling (103 p. 11). Musical listening is concerned with listening to more than one strand at a time, listening to melody, harmony, rhythm, timbre, locating the current voice within a community or even a cacophony of voices, staying with the chaos, locating the "now" with "what has been" and "with what may be", so that one's contribution, when made, because it is attentive, sacrificial

and focused, is appropriate and timely. Also important is listening to what is not being said (the musical rests).

Furthermore, just as the context in which musicians perform and an audience listens can affect the way music is interpreted, so too, can the spatial and temporal context of a pastoral conversation affect its interpretation. Critical listening is not just the prerogative of the pastoral carer, the auditor. As with music, so too it must be undertaken by the talker, the performer within the pastoral care setting. As well as being attentive and critical, listening must also remain detached. Paradoxically, just as "too much listening can get in the way of music-making" (p.171) so too, over-involved listening can blunt effective pastoral care. As with music it can prevent the pastoral carer, and therefore the pastoral relationship itself, from moving forward, being understood as gift and being lived in the present. In order to remain an abiding presence within healthcare, chaplains must be theologically rooted, bearing within themselves the memory of crucifixion and resurrection. To use a phrase from Kenneth Stevenson, effective pastoral care requires the pastoral carer to be "rooted in detachment" in which listening becomes a process of discernment in which cloud gives way to transfiguration, the cloud both obscuring and representing "the presence of God'' (Stevenson, 2007, p. 98). The telling of one's story to one who listens, as with "music, is not a luxury, it is essential" to our well- being, it is essential to our health (103 p. 29). It is only when listened to attentively that meaning making has any chance of beginning. The chaplain, from the perspective of Holy Saturday, offers the pastoral upbeat of resurrection hope.

2. **Balancing the public and the private person** – *reclaiming the spiritual space*

In attentively listening to another person, chaplains can find themselves being used as performance spaces in which is being worked out, and tested, what should be shared and what should remain private. Chaplains can also be expected to function as conductors where they are expected to facilitate that which is being shared and must themselves decide how best to manage the material shared within the pastoral encounter. As one interviewee said, “If I've shared something with you then it’s no longer just mine, it actually becomes yours to interpret how you wish” (102, p. 22). Is it to remain within the semi-private one to one pastoral relationship comparable with the music practice room, or does it require some more public liturgical working out comparable with the salon or concert hall? Chaplains must also decide how much they share of themselves in the process. In short, chaplains can find themselves tasked with the management of boundaried space, within which meaning-making can begin to take place. It is the presence of chaplains themselves that offer patients and staff a spiritual performing space… in which unrecognised feelings can be recovered and then rehearsed…where people can tell or re-frame their stories… and in the telling of those stories find healing.

In order for a chaplaincy to work effectively in hospital, it is vital that the chaplain has open access to the patients in their care (unless there is a medical reason which prohibits this, or the patient has specifically requested

that they do not receive chaplaincy visits). Adequate time needs to be made available to enable chaplaincy visits to take place. Ward staff need to understand the role that chaplaincy plays in the overall health and well-being of the patient, so that pastoral conversations are not interrupted unnecessarily. An adequate area needs to be set aside for functioning as a quiet room so that if the patient is well enough to leave their bed, confidential conversations can be conducted there. Away from the ward, there need to be ample opportunities for patients, their relatives, or members of staff to have access to a chaplain. There needs to be designated quiet areas, such as a chaplaincy office, chapel, multi-faith room, counselling or interview rooms, in which confidential conversations can be conducted by chaplains and others.

A designated chapel space also provides a location in which liturgy, especially that which arises out of a specific pastoral need, can take place as it enables “individuals, and the communities of which they are a part, to engage, unlock, become involved with, and to own the meaning of the situations and texts with which they come into contact…This is possible because liturgy… provides a medium for holding in a safe place that which is almost too hard to bear and offers out the hope of transforming it” (p.175). As one interviewee said of attending and celebrating the Eucharist, “I'm taking the spiritual winter with me, into that spiritual summer.” (001, p. 10)

Chaplains should seek to explain the need for, and value of “protected private space” for some aspects of pastoral care delivery. Having done this, chaplains then need to reclaim this “spiritual space” both philosophically, and practically, within the healthcare Trusts in which they work.

3. **Symbols and the facilitation of meaning** - *reframing the pastoral encounter*

In a health care environment that is becoming increasingly secular and where faith-neutral spirituality is gaining more credibility than religious faith, it is vital that healthcare chaplains remain theologically grounded. If not they run the real risk of having nothing theologically helpful to say at all, and of their presence within healthcare having become superfluous. The challenge for healthcare chaplains, operating a theological model of chaplaincy within an environment with secular expectations, is how to speak from that faith tradition in situations of brokenness and pain. This has been at the very heart of this present study. Clearly what chaplains believe underpins how they act; what they encounter in their pastoral relationships informs what they believe. I am suggesting that the chaplain is called upon to model nothing less than God him/herself, a God who can be seen, through the chaplain's presence at the bedside and elsewhere, to be involved with, and supportive of, humanity in the midst of its suffering. By practising the art of being “present”, the chaplain’s presence can become sacramental, experienced as an “outward and visible sign of an inward and spiritual grace” (B.C.P.,1970, p. 356).

In a health care environment in which the concept of health is viewed with increasing degrees of fragmentation, it is also vital that healthcare chaplains remain inclusively holistically grounded, in touch with the musical idea of communal performance. If health is not seen in terms of a communal performance with a number of different performers (including the patients themselves) with different parts to play within the healthcare score, the patient has no chance of maintaining their sense of personhood. This multi-layered communal performance enables the keeping alive of hope with the possibility of transformation, the adherence to a faith. It gives permission for people to be and become themselves, all of which take place within the music of affirming (sometimes even loving) relationships mirroring the unconditional love God has for his people. It points to the enfleshing of God in situations of brokenness and weakness (p. 50, 82, 137).

Each successive pastoral encounter requires the chaplain to reflect theologically upon it. To encourage this process of theological reflection chaplains need to be in touch with those skilled in listening to their own "cries from the heart" arising from the collage of experience with received tradition. This will help them to search authentically and possibly discern the presence of God and guard against the very real danger of being seduced by the "cries from the head" arising out of the secular institution in which they are working, in which God, whose existence is never acknowledged, can only be perceived as being absent. The chaplain is tasked with being a facilitator of meaning, assisting in the letting go of old symbols and helping in the discovery of new ones through which new meanings and new ways of

thinking about God are brought to birth. I am suggesting that the metaphor of music, the framing of pastoral encounters along with the symbols of musical performance, can provide one such recontextualisation.

In the light of this study, therefore, I have been arguing that it is important for chaplains to:

- Listen attentively within the pastoral encounter,
- Maintain the balance between the public and private person,
- Facilitate the discovery of meaning for patients and for those who care for them.

Coda

Conclusion

Central to this dissertation has been the idea of Collage (p.13 -14). Experiences born of darkness - suffering, sin and evil, surviving, human courage, the nature of God and that which gives life meaning - were collaged with examples of received tradition by way of generating an authentic discernment of the presence of God. (p.48). Experiences of darkness contained within case studies drawn from praxis were similarly collaged with those contained within healthcare literature (p. 78-79). Qualitative research, drawn from interview material, was collaged with theological reflection (p.82).

Music was explored as a “catalyst for collage” as it seemed to lend itself to the holding together of opposites, irrespective of whether there was any resolution of these opposing perspectives. It enabled text which proclaimed the presence of God, to be set alongside text which proclaimed God's absence (p. 152-153). The pastoral encounter (also functioning as a “catalyst for collage”) was similarly seen as a safe place where reactions arising out of the dichotomy between what should be and what is could be articulated, could be performed, the energy generated between them leading either to loss of meaning, or to the glimpsing of a reality lying beyond that which is immediately apparent (p. 178-179). Collage is so much more than an intermixing of differing elements which is an obvious critique that can be levelled against it and one which I am keen to address in this thesis. These

elements have within themselves the potential to be changed by being in the presence of the other. Collage is thus a potentially dynamic process rather than a merely static phenomena. Young roots this dynamic metamorphosis in that kind of inspiration which is born of, and lies beyond, perceived contradictions between texts, and between traditions of faith and current experiences (after Koestler, 1964 cited in Young, 1990, p. 2) (p.191). Lyall discerns this dynamic transformation when pastoral care creatively "tolerates ambiguity and ambivalence…that awakens the imagination and evokes awareness of new possibilities" (Lyall, 2000, p. 311) (p. 192).

Musically speaking, Young is clear that an authentic performance requires a right balance between "tradition and interpretation" (Young, 1990, p.45). The tradition of performing a piece, which is passed down successive generations, collages, collides and dialogues with any new insight that each subsequent performer brings. Begbie sees this to be particularly true with regards to jazz improvisation where "the musical elements supplied by the culture…and the idiom which contains and shapes them are interpreted in a manner that engages with the constraints of a particular occasion" (Begbie, 2000, p. 215). Because thematic variation is at the heart of jazz improvisation, Begbie sees improvisation as reminding us "powerfully of the futility of searching for a tradition-free environment of creativity" (Begbie, 2000, p. 217). Furthermore, this interaction between theme and variation "is not simply concerned with a past impinging on the present, but with generating a novel and fruitful future (Begbie, 2000, p. 220). Sometimes this

can represent something of a seismic shift, when in terms of composers radically reinterpreting tradition, Young refers to Schoenberg who having begun composing in the style of Wagner, overturned this tonal style of music in favour of atonal musical music (after Young, 1990, p.45).

Within my own musical composition entitled *Collage*, the great advantage of setting a variety of texts to music is that they can be broken up in such a way that connections are made between them which can either resonate or jar. The harmonic material can underline this, the tonal sections implying a guiding presence, the atonal sections perpetuating chaos (or more accurately, a different kind of order). The melodic material can also compound this sense of resonation or disjunction. The opening instrumental material (which serves as a kind of tonal love theme denoting the presence of God in our midst, which continues to exist, whether or not we acknowledge its existence or not), begins to 'infect' some of the unaccompanied atonal choral material to such an extent that the latter begins to take on its thematic shape. Another predominantly percussive instrumental group forms a kind of 'cantus firmus' figure throughout the work, the regularity of its rhythm signifying the persistence of the 'Why' question This is compounded by the humble triangle as it seeks to mimic both the sanctuary bell at Mass and the ringing of the Angelus, suggesting that the only way this question can be adequately answered, is by that which lies beyond what is immediately apparent. That reality, lying beyond perceived contradictions between texts, and beyond those between traditions of faith

and current experiences , lying beyond that which “simultaneously admits the truth of two contradictions, logically incompatible, ontologically equally necessary assertions”, that reality is indeed “a mystery beyond which human reason cannot penetrate” (Bulgakov, 1937, p.116 cited in Garrison, 1982 p. 27) (p. 153). That reality is God who him/herself is perfect collage, perfect antimony, perfect diversity in perfect unity, only approachable through brokenness, that which points to a wholeness beyond its liminal finite self.

Amongst the musical metaphors of healthcare chaplaincy explored above, perhaps the most intimate is that of the chaplain and patient caught up in the co-equal performance of a duet. Behind the imagery of chaplain as conductor, concert hall / chamber music salon, audience and performer lies God as the composer of creation enfleshed in performance within it. There needs to be a harmony between composer and performers. As the arts remind us (especially the performing arts of music, ballet and drama in that they are played out in real time), within us also there needs to be a harmony between the music of past, present and future. As Jesus' summary of the law reminds us there needs to be a harmony between love of God, neighbour and self. For those immersed in experiences of existential darkness, despite sensing God “through a glass darkly” (1 Cor 13:12 [AV]), in making clear that the healthcare chaplain has himself / herself a faith specific, communally focused, actively challenging, vicarious service - led view of chaplaincy, then the chaplain is called to mediate to others “face to face” God the Holy Trinity who is perfect harmony, perfect collage.

Appendix 1

St. John of the Cross - Dark Night of the Soul –

Prologue Pg 1-2 Stanzas of the Soul.

“1 On a dark night, Kindled in love with yearnings – oh happy chance! -

I went forth without being observed, My house being now at rest.

2 In darkness and secure, By the secret ladder, disguised -oh happy chance!In darkness and concealment, My house being now at rest.

3 In the happy night, In secret, when none saw me,

Nor beheld I aught, Without light or guide, save that which burned in my heart.

4 This light guided me. More surely than the night of noonday

To the place where he (well I knew who!) was waiting me - A place where none appeared.

5 Oh, night that guided me, Oh night more lovely than the dawn.

Oh, night that joined Beloved with lover. Lover transformed in the Beloved!

6 Upon my flowery breast, Kept wholly for himself alone,

There he stayed sleeping, and I caressed him. And the fanning of the cedars made a breeze.

7 The breeze blew from the turret. As I parted his locks:

With his gentle hand he wounded my neck. And caused all my senses to be suspended.

8 I remained lost in oblivion; My face reclined on the Beloved.

All ceased and I abandoned myself, Leaving my cares forgotten among the lilies.”

Appendix 2

Musical Forms

Monothematic forms

Fatasia

A freely flowing musical form which, although written down, gives the impression of improvisation. It is often placed before, and in contrast with, a fugue.

Theme and Variations

As its name suggests, this is a form which begins with a statement of the theme on which the whole of the piece is based; each subsequent variation being an embellishment of the original theme.. Variation can be achieved by filling in or drawing out the melody or rhythm, changing the harmony, the key, or the time signature. Often the movement will end by a restating of the original theme.

Ground Bass or Passacaglia

This is a form of Theme and Variation in which the same repeated note pattern (Theme) occurs initially in the bass part (but subsequently can occur

in any part) and where variety is achieved through the constantly changing other parts).

Fugue

This is the apotheosis of monothematic forms in which a theme is stated, then stated again coming in five notes higher, then stated again at the octave, then stated again at various intervals. Once the theme has been stated it then needs to harmonise with the next statement of the theme so the music builds up in a kind of lattice work structure. Because the fugal passages can be quite intense, these are punctuated by other musical passages known as episodes picking up on a rhythmic and melodic figure that has occurred before and developing it before the fugual subject is stated again.

Dualistic forms

AB Form

The simplest example where more than one musical idea is used is the strophic form of verse and and chorus. Whereas each verse may have the same music but different words, and each chorus will have the same words and music, coupled with the fact that the verse of a song is often sung by a soloist or solo group whilst the chorus is likely to be joined in by all present, there is added contrast established between the two sections. Both sections

are essential to the whole song but remain distinct. There is no interplay between them.

ABA Form

All that is necessary to convert a strophic song into ABA is for it to begin and end with its chorus. [This raises the very important question concerning whether it is ever possible to truly repeat anything at all. The last chorus, although it may sound the same as the first chorus, feels different because of the experience of having been stated before (so it is not new to the ear), and because of hearing it in relation to the different material of the verse.]

Rondo

(ABACADetcA) This form is a further development of the AB and ABA forms in which each 'verse' has different music, the unifying factor being the recurrent 'A' material with which it must begin and end. A refining of Rondo form is the Bridge Rondo in which the second half of the form is a mirror image of the first half (eg ABACABA).

Sonata Form

This is the apotheosis of dualistic forms. Just as fugal form reached its zenith when faith was at its strongest in that period immediately before the Enlightenment, so Sonata Form grew out of the 'thesis, antithesis, synthesis' ideas of the Enlightenment. A sonata form movement owes its drive to the harmonic journey that takes place within it. Sonata Form can be divided into three sections: Exposition, Development and Recapitulation. A refining of Sonata Form is the Bridge Sonata Form in which, in the Recapitulation the second subject appears before the first.

Appendix 3a

Patients in hospital

Participant Information Sheet

You are being invited to take part in a research study as part of a student project for the degree Doctor of Practical Theology. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the research?

Rev. Gregory Clifton-Smith, (D.Prof Student year 5)

School of Theology and Religious Studies,

The University of Chester,

Parkgate Road,

Chester, CH1 4BJ

Title of the Research

'In the context of health care, where is God in the “dark places” of human experiences?'

What is the aim of the research?

Within the hospital setting, very little has been written on the ways in which individuals talk about experiences of illness, bereavement or loss that they have had in their lives (which can, in the case of those with a religious faith, include a sense of the absence of God) and the methods they use in trying to cope with them. My hope is that in seeking to investigate how people talk about these painful experiences in the context of being cared for in hospital, this may have a direct application as to how more effective pastoral care (by hospital chaplains and the like) may be provided in the future.

Why have I been chosen?

You have been chosen to be interviewed because you are someone who has come forward as presently experiencing a period of illness, bereavement or loss in your own life

What would I be asked to do if I took part?

You will be asked to take part in one confidential taped interview conducted by me If difficult issues are raised during the course of the interview, support will be provided if required by a colleague.

What happens to the data collected?

Once the interview has taken place it will be anonymised and transcribed into written text .

How is confidentiality maintained?

The taped interviews and transcriptions will be stored confidentially. A code number will be given to each person who has been interviewed. The key to the code will be stored separately from where the transcribed interviews are stored. Once the tapes have been transcribed, the tapes will be wiped clean at the end of the study.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself

Will I be paid for participating in the research?

No

What is the duration of the research?

One interview which will last no longer than an hour.

Where will the research be conducted?

The interviews will take place in hospital in a room in which only the researcher and interviewer are present and which cannot be overheard by any third party.

Will the outcomes of the research be published?

The interviews will be incorporated into a dissertation and published in an appropriate peer reviewed journal.

Who has reviewed the research?

The research has been reviewed by the IOW, Portsmouth & South East Hampshire REC.

Criminal Records Check (if applicable)

Not applicable (but as a requirement of his present employment the researcher has already been cleared by the Isle of Wight NHS Primary Care Trust)

Contact for further information

The Rev. Gregory Clifton-Smith,

The Chaplaincy Office,

St. Mary's Hospital,

Newport,

Isle of Wight,

PO30 5TG

Tel.

What if something goes wrong?

Please contact at me at the above address

If you wish to make a formal complaint about the conduct of the research please contact Professor Robert Warner, Dean of Humanities, University of Chester, Parkgate Road, Chester, CH1 4BJ.

University of Chester

Appendix 3b

Christians in public life

Participant Information Sheet

You are being invited to take part in a research study as part of a student project for the degree Doctor of Practical Theology. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the research?

Rev. Gregory Clifton-Smith, (D.Prof Student year 5)

School of Theology and Religious Studies,

The University of Chester,

Parkgate Road,

Chester, CH1 4BJ

Title of the Research

'In the context of health care, where is God in the “dark places” of human experiences?'

What is the aim of the research?

Within the hospital setting, very little has been written on the ways in which individuals talk about experiences of illness, bereavement or loss that they have had in their lives (which can, in the case of those with a religious faith, include a sense of the absence of God) and the methods they use in trying to cope with them. My hope is that in seeking to investigate how people talk about these painful experiences in the context of being cared for in hospital, this may have a direct application as to how more effective pastoral care (by hospital chaplains and the like) may be provided in the future.

Why have I been chosen?

You have been chosen to be interviewed because you are someone who has come forward as presently experiencing or having experienced a period of illness, bereavement or loss in your own life

What would I be asked to do if I took part?

You will be asked to take part in one confidential taped interview conducted by me If difficult issues are raised during the course of the interview, support will be provided if required by a colleague.

What happens to the data collected?

Once the interview has taken place it will be anonymised and transcribed into written text .

How is confidentiality maintained?

The taped interviews and transcriptions will be stored confidentially. A code number will be given to each person who has been interviewed. The key to the code will be stored separately from where the transcribed interviews are stored. Once the tapes have been transcribed, the tapes will be wiped clean at the end of the study.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself

Will I be paid for participating in the research?

No

What is the duration of the research?

One interview which will last no longer than an hour.

Where will the research be conducted?

The interviews will take place at home or at a place of the interviewee's own choosing, in a room in which only the researcher and interviewer are present and which cannot be overheard by any third party.

Will the outcomes of the research be published?

The interviews will be incorporated into a dissertation and published in an appropriate peer reviewed journal.

Criminal Records Check (if applicable)

Not applicable (but as a requirement of his present employment the researcher has already been cleared by the Isle of Wight NHS Primary Care Trust)

Contact for further information

The Rev. Gregory Clifton-Smith,

The Chaplaincy Office,

St. Mary's Hospital,

Newport,

Isle of Wight,

PO30 5TG

Tel.

What if something goes wrong?

Please contact at me at the above address

If you wish to make a formal complaint about the conduct of the research please contact Professor Robert Warner, Dean of Humanities, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Appendix 3c

Musicians

Participant Information Sheet

You are being invited to take part in a research study as part of a student project for the degree Doctor of Practical Theology. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

Who will conduct the research?

Rev. Gregory Clifton-Smith, (D.Prof Student year 5)

School of Theology and Religious Studies,

The University of Chester,

Parkgate Road,

Chester, CH1 4BJ

Title of the Research

'In the context of health care, where is God in the “dark places” of human experiences?'

What is the aim of the research?

Within the hospital setting, very little has been written on the ways in which individuals talk about experiences of illness, bereavement or loss that they have had in their lives (which can, in the case of those with a religious faith, include a sense of the absence of God) and the methods they use in trying to cope with them. My hope is that in seeking to investigate how people talk about these painful experiences in the context of being cared for in hospital, this may have a direct application as to how more effective pastoral care (by hospital chaplains and the like) may be provided in the future.

Why have I been chosen?

You have been chosen to be interviewed because you are someone who has come forward as being proficient at interpreting the painful experiences of life and communicating them to others through the medium of music. You may or may not have also experienced a period of illness, bereavement or loss in your own life.

What would I be asked to do if I took part?

You will be asked to take part in one confidential taped interview conducted by me If difficult issues are raised during the course of the interview, support will be provided if required by a colleague.

What happens to the data collected?

Once the interview has taken place it will be anonymised and transcribed into written text .

How is confidentiality maintained?

The taped interviews and transcriptions will be stored confidentially. A code number will be given to each person who has been interviewed. The key to the code will be stored separately from where the transcribed interviews are stored. Once the tapes have been transcribed, the tapes will be wiped clean at the end of the study.

What happens if I do not want to take part or if I change my mind?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time without giving a reason and without detriment to yourself

Will I be paid for participating in the research?

No

What is the duration of the research?

One interview which will last no longer than an hour.

Where will the research be conducted?

The interviews will take place at home or at a place of the interviewee's own choice, in a room in which only the researcher and interviewer are present and which cannot be overheard by any third party.

Will the outcomes of the research be published?

The interviews will be incorporated into a dissertation and published in an appropriate peer reviewed journal.

Criminal Records Check (if applicable)

Not applicable (but as a requirement of his present employment the researcher has already been cleared by the Isle of Wight NHS Primary Care Trust)

Contact for further information

The Rev. Gregory Clifton-Smith,

The Chaplaincy Office,

St. Mary's Hospital,

Newport,

Isle of Wight,

PO30 5TG

Tel.

What if something goes wrong?

Please contact at me at the above address

If you wish to make a formal complaint about the conduct of the research please contact Professor Robert Warner, Dean of Humanities, University of Chester, Parkgate Road, Chester, CH1 4BJ.

Appendix 4

CONSENT FORM

If you are happy to participate please complete and sign the consent form below

1. I confirm that I have read the attached information sheet on the above project and have had the opportunity to consider the information and ask questions and had these answered satisfactorily.
2. I understand that my participation in the study is voluntary and that I am free to withdraw at any time without giving a reason and without detriment to any treatment/service
3. I understand that the interviews will be audio-recorded
4. I agree to the use of anonymous quotes
5. I agree to my GP being informed of my participation in the study
6. I agree that any data collected may be passed to other researchers

I agree to take part in the above project

Name of participant		Date		Signature
Name of person taking consent		Date		Signature

Appendix 5a

Structured Questions to be used in interviews. Version A (Patients / Christian public Figures)

I would like to begin by asking you about your illness / bereavement:

1. Could you say something about the onset of *your / their* illness. How did you first become aware that *you / they* were unwell?

2, How did it develop?

3, Could you briefly describe the treatment plan? Was it subject to change?

4. What were your feelings after diagnosis prior to the illness developing?

5. As you think back *over the course of your illness / from this moment in time*, have those feelings changed in any way? If they have, could you tell me how?

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about *your / their* illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

7. Did you find that *your illness / their illness and subsequent death* affected the way that family, friends and colleagues related to you?

8. What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your *illness / bereavement* had an effect on your relationship with others who are *unwell / bereaved*, both in your public role and your private encounters?

10. Has your *illness / bereavement* changed your sense of priorities? Has it caused you to make any major changes in your life?

11. In the context of *your illness and recovery so far / your loved one's illness and subsequent death*, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

12. When thinking of your experience of *illness / bereavement* within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

13. Would you say that on balance you have been able to see your *illness / bereavement* in a positive, a negative or a neutral light?

14. How do you feel about the future?

Thank you very much for agreeing to be interviewed.

Appendix 5b

Structured Questions to be used in interviews.

(Musicians)

I would like to begin by asking you about your development as a professional musician:

1. Could you say something about your professional life as a musician. When did you first become aware that music was to play a pivotal role in your life?

2. What are some of the key world events that have had a deep effect upon you as a person and therefore as a musician?

3. Who have been the key musical figures that have shaped your own musical development?

4. What have been those elements of your musical training that have proved of most use in the exercise of your professional musical life today? As well as being technically competent, what informs your ability to successfully interpret emotionally charged music, particularly that seeking to convey life's dark side?

5. What of your own life experiences do you bring to your professional life that have helped shaped you into the musician that you have become?

I would now like to focus on the theme of the painful experiences of life explored in music.

6. What are some examples of compositions that you can think of that for you in particular address painful human experiences such as loss, desolation and isolation?

7. Have your compositions/performances ever affected the way that family, friends and colleagues related to you?

8. Have you ever felt the need for particular support yourself when creating/re-creating 'dark' pieces of music? If so what form has this support taken?

I would now like to explore the effect that the painful experiences of life explored in music can have on the way that you live your life day by day.

9 Do you find that seeking to interpret life's dark experiences gives you any better understanding of those who experience life shadow side 'in the raw' so to speak?

10. Has performing such pieces rooted in life's painful experiences ever changed your own sense of priorities? Has it caused you to make any major changes int your life?

11. When immersed in interpreting, through the medium of music, these dark experiences of life, what affect [if any] has this had on your outlook on the world, such as a religious faith or world view.

12. When exploring the painful experiences of life in music, have you found yourself using any recurrent images or symbols? If so, could you tell me what they are?

13. What role do you think that the arts in general, and music in particular, have in exploring every kind of human encounter? Can uncovering the darker side of human life, be seen in a positive negative or neutral light?

14. Can there be any mileage to be gained by the arts, including music, taking a contrary position so that rather than uncovering that which is destructive, seeks to uplift the human spirit by focusing on the divine, however that be understood ?

Thank you very much for agreeing to be interviewed.

Appendix 6 *HAD Scale 1*

HAD Scale 2

HAD Scale 3

HAD Scale 5

Reference:

Zigmond and Snaith (1983)

7a	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Themes A	Illness/ loss reap-praisal of priorities	Unpred ictabili ty of future	Public verses private person	Context of illness / loss	Positive aspects of suff-ering	Neg. aspects of suff-ering	Lifechan ging nat ure of ill ness/self	Support litugical and musical	Support people	Isolation	Doing vs Being (helpless ness)	Finding out	Bad news broken badly	Action driven treat-ment
1	x	x	x	x	x	x	x	x	x	x	x	x		x
2	x	x	x	x	x	x	x	x	x	x	x	x	x	x
3	x	x	x	x	x	x	x	x	x	x		x		x
101	x		x		x	x	x	x		x	x			
102	x	x	x	x	x	x	x	x	x	x	x			
103		x	x					x		x	x			
201	x	x	x	x	x	x			x	x		x		x
202	x	x	x	x	x	x	(x)	x	x	x		x		x
203	x	x	x	x	x	x	x		x	x				x
204	x	x	x	x	x	x	x	x	x	x	x	x		x
205	(x)	x	x	x	x	x	x		x	x				
206	x	x	x	x	x	x	x		x		x	x		x

	15	16	17	18	19	20	21	22	23	24	25	26	27	28
Themes	Coping (Surviv-ing)	Trans-forming role of Hospice	The role of faith (redemp tive?)	The death scene	Griev-ing	Support of peop-ple after death	Bereave ment as learning curve	Another new begin-ning	The role of humour ?	Illness as a battle	Too much & too little care	Crossing bound-aries pos/neg	Child-hood frustrat-ions	What I wanted
1	x													
2	x	x	x	x	x	x	x	x			x			
3	x		x					x	x	x	x	x		
101	x		x										x	x
102	x		x		x	x		x	x			x	x	x
103			(x)										x	x
201	x		x		x				x					
202	x		x					x		x	x			
203	x		x								x			
204	x		x						x		x			
205	x		x						x					
206	x		(x)		(x)				x					

	29	30	31	32	33	34	35	36	37	38	39	40		
Themes	Fascilit-ating music in others	Context of com-posing-external	Context of com-posing-personal	Others' works on pain-ful exp.	Import-ant influ-ences external	Music as a means of red-emption	Symbols	Music, a vehicle for pain-ful exp.	The own ership of meaning	Music – an aid to listening	The role of chance	Tradit-ion verses praxis		
1														
2														
3														
101	x	x	x	x	x	x	x	x						
102	x	x	x	x		x	x	x	x	x				
103	x	x	x	x	x	x	x	x	x	x	x	x		
201														
202							x							
203									x					
204							x							
205							x							
206							(x)							

7b	1	2	3	4	5	6	7	8	9	10	11	12	13	14
Themes B	Illness/ loss reap-praisal of priorities	Unpred ictabili ty of future	Public verses private person	Context of illness / loss	Positive aspects of suff-ering	Neg. aspects of suff-ering	Lifechan ging nat ure of ill ness/self	Support faith	Support musical	Support people	Isolation	Doing vs Being (helpless ness)	Finding out	Coping (Surviv-ing)
1	x	x	x	x	x	x	x	x	x	x	x	x	x	x
2	x	x	x	x	x	x	x	x		x	x	x	x	x
3	x	x	x	x	x	x	x	x	x	x	x		x	x
101	x		x		x	x	x	x	x		x	x		x
102	x	x	x	x	x	x	x	x	x	x	x	x		x
103		x	x					x	x		x	x		
201	x	x	x	x	x	x		x		x	x		x	x
202	x	x	x	x	x	x	(x)	x	x	x	x		x	x
203	x	x	x	x	x	x	x	x		x	x			x
204	x	x	x	x	x	x	x	x		x	x	x	x	x
205	(x)	x	x	x	x	x	x	x		x	x			x
206	x	x	x	x	x	x	x	(x)		x		x	x	x

	15	16	17	18	19	20								
Themes	Griev-ing	Another new begin-ning	Illness as a battle	Too much & too little care	Symbols	The own ership of meaning								
1														
2	x	x		x										
3		x	x	x										
101					x									
102	x	x			x	x								
103					x	x								
201	x													
202		x	x	x	x									
203				x		x								
204				x	x									
205					x									
206	(x)				(x)									

7c	1	2	3	4	5	6	7	8	9	10				
Themes C	Illness/ loss reap-praisal of priorities	Unpredictability of future	Public verses private person	Context/ effect on self of illness	Pos. & neg.suff. Level of care	Support faith music & people	Isolation	Illness-active or passive	Coping including grieving	Symbols & meaning				
1	x	x	x	x	x	x	x	x	x					
2	x	x	x	x	x	x	x	x	x					
3	x	x	x	x	x	x	x	x	x					
101	x		x	x	x	x	x	x	x	x				
102	x	x	x	x	x	x	x	x	x	x				
103		x	x			x	x	x		x				
201	x	x	x	x	x	x	x		x					
202	x	x	x	x	x	x	x	x	x	x				
203	x	x	x	x	x	x	x		x	x				
204	x	x	x	x	x	x	x	x	x	x				
205	(x)	x	x	x	x	x	x		x	x				
206	x	x	x	x	x	x		x	x	(x)				

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Supplementary Material:

A Interviews in full;

B Collage

Interviews

Transcription 001.

1. *Could you say something about the onset of your illness. How did you first become aware that you were unwell?*

Well. In the summer of 2005, I was aware that I had put on a lot of weight, and thought that my lethargy and sweating was because of that, Under normal circumstances before I was ill, sweating was something that I'd simply inherited. At the beginning of September, I had a very busy weekend, and I just poured with sweat. So I went to the doctor on the Monday, realising that my pulse was racing, and he put me on pulse pills. And as I left his room, he said oh by the way, you might as well have a blood test. So I went for the blood test on the Wednesday and I was all set to go to Denmark, for a bishops consecration on the Friday. On the Thursday morning he rang and said that haematology are very concerned about the blood levels, and go to haematology at (N) Take some overnight stuff. They did blood tests and bone marrow biopsy which was absolutely agonising, everything was agonising. They told me you'd got acute myloid leukemia.

2. *How did it develop?*

Well, I was put on four courses of chemotherapy and they'd seem to have done the trick. But I relapsed the following May, and so I was put on the bone marrow programme in (N) and got ready for that. I was put on that through the summer and the Autumn. It was very very strong. And had the bone marrow at Christmas. But then I relapsed again the following summer, again

after five months, and was urged to have another bone marrow transplant with the same donor, who was willing to give, from Italy. That was amazing. He wrote me a lovely card actually after the second transplant. We're not allowed to know who we are, I sent a thank you after each. And they screen it to make sure that there's nothing that would indicate who I was or anything like that. And they decided that because of my physique, my system handles drugs quickly and easily, so they decided to provoke the graft versus host straight away, unlike after the first bone marrow, and of course I've had it virtually ever since.

And the idea being that graft versus host keeps the disease at bay while your immune system is building up. They don't know how or why, but that's what the statistics show. So I've had it everywhere. I had the choice. And I remember when he rang me after to test me, and he said that it was not good news. My first reaction was how long have I got, but he said look, you are very strong. And it is possible - you know, we're not talking about three to six months more to live, but we are talking about a potential cure. So, it's been a bit of a roller coaster, and of course I've lost a lot of weight. The thyroid thing – you know I've had everywhere. It starts here and goes right down to my feet. That's all very well and that's sorted out now. And it's been on my skin and then when it got to my head of course it took over on the inside of my mouth and then it went to my eyes so that I couldn't see very well, giving me cataracts, one of which is treated. I'm now getting used to seeing without glasses I've had reading glasses since I was twelve. I'm now

59. it's very very strange! And I lost my hair after the second, no the first transplant , or was it the second I think? The impression that I'm getting is that the first transplant went too well. I actually put on weight while I was in hospital. And I'm not criticising in any way , in ANY way the people who have been treating me. I can't praise them too highly, but you just learn in retrospect and so they decided to give me a hammering, and this is what they have done. And I'm alive to tell the tale. I'm coming up to the second anniversary. The second anniversary is not especially significant, but the fact that I've lasted two years, the longer I will out it, the less likely it is to return.

I decided straight away that when I was diagnosed there was a desire for me to let people know., and I decided to be candid about it. I'm not by nature an agoniser in public. I'm actually a very private person. But I decided as a church leader diagnosed with a life threatening illness it was quite right and proper that I should have a conversation with myself and with those treating me, those close to me, …. about what this was doing. And I knew that many people would be helped by this because they would say well I'm now permitted, Christianly, to question and to probe . I also knew that others would find this difficult and a little near the bone. You know, church leaders should perhaps not do that. I've not heard anyone say that but I wouldn't be surprised. You get a cross section, and there is a bond, an unmistakable bond between all cancer sufferers. The Dean of (N), (N) is in remission and that's where we will be going to church. There is this bond between (N) and me . And I've confirmed someone …. who had leukemia. She came up to me

after the service. And I knew straight away from her face, you know, it is quite extraordinary.

3, *Could you briefly describe the treatment plan? Was it subject to change?*

Yes, decisions were taken on different sorts of chemotherapy and before the second transplant, I had chlofaradine which is normally I think used on children and young people. And it was decided that I could take it. They have used it on patients that were older. … I'm not quite sure how they found the money to get it. … But I never at any stage got the impression that they were spending thousands and thousands of pounds on me to keep me alive for just three more minutes … The whole thing has been about cure. But I had different sorts of chemotherapy and different sorts of treatment for all these side effects. Going into relapse after the Chrism Mass (year?) was very tough. The last Chrism Eucharist I got everybody to lay hands on me. It's funny that, I only told the Dean, I didn't tell anyone else. And I said to (N) I just felt that it was right that I'd ask them to do this before the Peace or before the Renewal of Vows I think. Yes. And there was an absolute rush, there was a surge forward in the cathedral . Everybody went forward – very moving.

4. *What were your feelings after diagnosis prior to the illness developing?*

Well I knew from the tests that there must be something serious. And it was a ward round. One of the doctors smiled and Sarah smiled . Its either going to be the end, or back to normal or early retirement. And I heard afterwards that that was written down in my file as a kind of A1 attitude, total realism. That either I was going to die and that would be it, and we'd only just put down an offer and negotiated a retirement house with a mortgage at Chichester, because my mother died the year before, (N) helped (N) pursue that, so we were living in a kind of impasse, trying not to run away from it. My mother died, and it took me some time because it was in the middle of all the All Saints-tide confirmations. You know what people are like. Take it easy, but if you don't do this, this and this. I mean, I couldn't get any one else to do them. And then we had the business of getting rid of all her estate. So that previous year had actually been quite demanding, but you know, that's what life is like. I don't go for the psychologist's view that leukemia is a result of stress, that is an absolute load of tosh. Leukemia - it's there, because it's there, because it's there, because it's there. I'm a tough old thing.

5. *As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?*

No. I mean I think the feelings have been very much the family drawing closer together. We are close anyway and particularly at times when you know I was a bit rough. I have had excellent pastoral care from hospital chaplains and others. I decided not to have a rota of priests looking after me, but I have been very well looked after. The (N) Hospital Chaplains have been

terrific but they operate with my licence. So I got (N) my Rural Dean in(N). He's an old friend. So he came in when I was in (N). In (N) I was looked after by the chaplain, (N) and he was just brilliant. And in fact in this last..... after Christmas, he really helped me to sort all sorts of things out that needed to be sorted out about my life and my past – all sorts of things. And that will either prepare me for death, but at that time, I needed to talk to him in a big way, it was clear that I was going to survive. But all last autumn, I was wrestling with whether to retire or not. I was getting anxious and I knew other people were. But the (N) couldn't just ring up the pensions Board and ask about retirement. You know, you are in a very public position, That is the problem. I don't think the church has really grasped that bishops have to find their own support.

6. *Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?*

I was quite clear, everybody should know straight away and almost to the point of overkill I think, I kept colleagues aware of details and that was part of the coping mechanism. But also honesty. I think if anything, I overdid the health bulletins. But that's my natural candour. The people's perception of me, I think you need to talk to others about that, but what I sense is, people have seen a larger than life public figure whom they know to a greater or lesser extent as a human being, going through an experience of very considerable vulnerability. And I think that's bound to be noticed, I know it's

been noticed and I was talking to (N) about it before Christmas and the effect of the illness upon me has both toughened me and softened me. I put this into a sermon I preached at (N)'s Institution at (N) on 5th March. You can look it up on the website – it's actually a funny sermon. It's all about John Mortimer's 'Horace Rumpole'. My biggest regret when I was in Guildford, the last show he appeared in at the Evelyn Arnaugh Theatre where I was chaplain, he didn't say come in when I knocked at his door. I did the round of the cast, he probably didn't hear me. But look that sermon up. What it does is it toughens you because you've actually got to cope with a very difficult unprecedented situation. And let your family help you and take your family through it. But it also softens you, because you have to cope with your own vulnerability and weakness and accept it. I have to accept now there are certain things I can't do and probably will never be able to do in the same way. Well patience was never one of my virtues (N) but I think it's made me a bit more tolerant , because I've had to lie in that bed . Not very much, but I'm just aware of.... I still get cross and impatient about injustice. Particular sorts of incompetence and and the sheer silliness of the church. I remember saying to (N) that for example I find the two presenting issues in the church increasingly irrelevant because on the one hand I've had numerous ward rounds where the consultants, and the registrars, and the SHO's and nurses were all women. And I have been ministered to in different ways hospital wise by people who are gay. And I found the whole thing, and you can put this down, I find the whole package of opposition to the ordination of women and about the whole preoccupation with the gay issue just... I mean before the illness I was of this point of view anyway, but I have lost patience with it.

And the only thing, I mean, I've got very good friends, people like (N) people like (N) who are against the ordination of women And I fully appreciate and realise that issue is straining friendships as you know. The House of Bishops is agonising over it. If you want to find out what (N) thinks, I said this in the robing room at the House of Lords on Tuesday to (N) and (N) and (N). You know the endless debate about how we make provision about the women – we are losing more credibility in the eyes of the world. Just the sheer... you know, the amount of time and nervous energy that has been put into all of that, that's one of the reason I insisted on having that thing that I couldn't attend with (N) and (N) on the economic crisis in the cathedral. A hundred people turned up. It was important to say “Look this is what we should be concerned about”. It's the same with expenses and constitutional reform. Constitutional reform takes hours, days of parliamentary time. And actually it isn't what people want, they want six of the best for those who have offended, a rigid system that they must subscribe to and they want the economic crisis dealt with. Because if they don't deal with it, people like me are not going to get bone marrow transplants. I said the other day watching the news on, was it Wednesday, on the news, I've got in just in time.

7. Did you find that your illness affected the way that family, friends and colleagues related to you?

The family. Not the children and (N), I mentioned that already. Nor colleagues actually, because we're a close knit bishop's team. Wider family, deeply concerned. Friends, some opted out. I'm talking about more,

acquaintances, others were there and professionally others again just wanted to know what was going on. You know what clergy are like, bishops aren't much different -because we're clergy. And they obviously want to know because they want to let other people know. But at no time did I get the feeling of being sent to Coventry. An amazing amount of concern for me from fellow bishops. But then as things went on and on they realised that either things were very difficult and they'd expressed their concern. But I have got a number of bishops whom I'm pretty close to. In talking about the isolationism, one of the things bishops need to do is to meet other bishops. And whilst I was off, it often coincided with bishops meetings so I couldn't get to them. So I've relied on contacts with other bishops on the phone.

8. *What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?*

I think it was knowing that people were praying for me. One of the most difficult bits about the first Christmas was that neumenitis meant that I was in a mask for a week which is the most ghastly experience I have ever had in my life. And I didn't want to have the mask on and I wanted to take it off, but the nurse said if you don't keep the mask on, you won't make it. And so I wasn't actually able to speak to people, only write. And I think, although Sarah didn't let on I was in ICU, people realised by her demeanour that it was serious. Knowing that people were praying for me and feeling that sense of love and concern, and people's letters and cards – there was a deluge at the beginning, an absolute deluge – and (N) coming to see me most days.

We spent more time with each other than we had ever spent before – its a very close marriage. And seeing the family, and seeing friends. And the community of faith. And whilst I've not been able to go out and about, (N) and I have been able to celebrate the eucharist together, the two of us in the chapel. This Sunday's free, last weekend was too busy so I will celebrate the eucharist, and our youngest son who is staying with us will come too. I want to make it very clear, especially with the icon post card, this is not just my private chapel, but it belongs to the diocese. That's why it is consecrated to All Saints.

The sermon that I preached last year on Corpus Christi Day in (N), is all about my eucharistic life in hospital. You'll also find references to my little book “Take, eat” I'll give you a copy when you go. The (N) sermon, (N) the chaplain at (N), saw it on the web site and used it . That in the midst of all the Anglo-Catholic ritual, I was describing a very threadbare eucharistic life, a very intincted, no tat, the simple bare necessities, you know the kind of thing that you do, and that was my diet. And saying Mattins until last Autumn when I wasn't able to read because of eyes, In saying Mattins, I had to put my book down twice because people came for this, that or the other. Maintaining the priestly life. But now I'm back in the chapel regularly every day, twice a day, I'm taking the spiritual winter with me, into that spiritual summer. I'm quoting Augustine again, “Be an ant of God” - wonderful. Pile up the food so that when you haven't got enough, you can cope. I've said to (N), I don't think he entirely liked it, there have been stages in the illness when I have felt beyond

the community, beyond the church ,beyond the faith and actually at times, beyond myself. I'm not talking about possibly dying but the sheer weight of the awfulness of it all. And I think there's a reference to that in the little book on the eucharist actually. There's a sense of being completely stripped and purged. I don't want to sound over dramatic and it is certainly not meant to sound like theological self-pity, because I don't go for that. There's a sense in which that is a very clerical disease. The necessary death that you have to do from time to time and that might be drug induced. The thyroid, you know, I was warned can make me a bit emotional but I would have got emotional anyway. But it's just being in a sort of 'no-man's- land' and a kind of listlessness. Angela Tillby's book on the Seven Deadly Sins which I thoroughly recommend. It's quite hard work but it's very perceptive. Also a serious work of theology. People don't realise that. I actually reviewed it for the Church Times. But she says that sloth is the one evil thought that takes over the whole body, the whole personality. It's everything. So I suppose it may be a form of sloth. But I think it is an extreme, a condition in which sloth is involved. And the whole business about who you are and where you are and the people you love – I don't know how you put it into words.

One of the reasons why my favourite Old Testament prophets is Ezekiel is because he's so off beat., I mean seriously off beat. And I suspect, a bit bi-polar. And the fact that the Rabbi said "Don't let anybody under 30 read the opening vision of the four living creature which I absolutely adore , which of course meant that they jolly well did read it. But he was off beat, and very

creative people are often like that. Take Mozart! The massive Danish figure Nicolai Gruenwig a hymn writer, he was a bit bi-polar. And Richard Baxter, One of the hymns he wrote, was it When I survey the wondrous cross, was when he was in a place of real wastefulness? I think one of the reasons that people find hymns express the downside of life is because - hymnody is more popular than the psalter because it is metrical. You can remember it more easily. But going back to the daily offices, the psalms were just wonderful because they offer every single kind of human experience, widely differing human experience, and so you have human experience in its entirety offered to God.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

Yes In Southampton, I was always in my separate room and nearly always in an isolated room where you had to go through one door and then through another, so I didn't have very much to do with other patients. Of course, I would meet them at clinics. And we'd have these slightly odd conversations when we would try and update each other how we were getting on without being in competition Quite tricky that one. I've had my belly full of bad luck, but I've also had the most incredible “success rate” But certainly with cancer patients there is a very definite bond. And our youngest daughter (N) was over recently and is determined to arrange a concert in London this September in aid of Leukemia research. It seems to be gathering amazing momentum. We're certainly intending to go up to it.

10. Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?

Yes, it certainly brought retirement to a head, as you know I announced my retirement in a pastoral letter last February. That was hard, it was the day before Diocesan Synod met. Planning for my retirement made me think about the aging process in general as a process of continual pruning, each bit of life preparing you for the next part that was to come. God as the vine dresser. Although I have already begun saying goodbye to people around the diocese, and I am finding it very hard. But I know it's right, and I know that it's got to happen.

11. In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

One of the things that has become confirmed for me is the smashing of the secularist dream. In the fall out from 9/11 and the present economic crisis, there is such an amount of interest in spirituality. My illness has made me more aware of this dilemma. And it's important to work with other Christians. Take the Embryology Bill for example. I spoke in the recent debate in the House of Lords. Christian from across the house spoke to this bill as well as the bishops. And they are listened to. And I go back to my little book “Take, eat” and its no tat eucharistic life.

12. When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

For me, music was so important, music both with and without words. Especially the music of Bach. In hospital, I had Classic FM on most of the time. I'd listen to this once Sarah had gone home in the evening. I probably feel asleep with it on. But the prayers in the liturgy were important too and repeated psalms. But there were also the prayers drawn out of yourself and those prayers which drew the rest of the world in.

13. Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?

Never in a neural light, but both negative and positive. The negative was something to do with being a burden. And it was a struggle, I had to face my own demons. As I said before, one of the hospital chaplains, (N), was with me at some pretty low moments in my illness. But there was a positive in all this. There were huge blessings. The love and care of family and friends and of the doctors and the nurses.

14. How do you feel about the future?

Paradoxically I feel full of hope. I've survived. There is more uncertainty concerning me dying in the short term. With every passing day, my dying soon is looking less likely. But of course, this could all change just like that. It is difficult to give up the job. Moving from the house is going to be a physical and emotional and spiritual challenge. But God has something else in store for me to do and to be. Life is full of transitions.

Thank you very much for agreeing to be interviewed.

Transcription 002

I would like to begin by asking you about your wife's illness?

1. Could you say something about the onset of your wife's illness. How did you first become aware that they were unwell?

(N) died on 5th February 2005 As luck would have it, I was due to write my 'thought for the month' slot in (N), our diocesan newspaper, shortly after that. And so I talked about (N).[Look at the (N) for April 2005 and look at (N)'s 'The Last Word'.] When did we first become aware that something was wrong? Well, working back four years from then, (N) had to go for a routine breast screening whilst we were living in (N) following a lump being felt., by me actually. (2001) The scan was missed by two years. It should have picked this up when 50. it picked it up two years late. And then all we could do was wait. It was a horrible moment when (N) was called back for a further test, a biopsy, which we had to wait two weeks for. We did a lot of walking around the back streets of (N) when we waited for the results of this one. When we were told that (N) needed another scan, there was a stunned silence. We knew something difficult was going on. It was simply too difficult to talk about. Horrible. And then we were told that they had found lumps in both breasts. It was cancer. The doctor told us this news in a public place, he unravelled the computer print out of the breast scan in front of us, we had no time to digest what he was saying. It was all very matter of fact, all very 'clinical'. There was a starkness about this whole episode. And the nurse

didn't say a word. (N) needed a lumpectomy. She asked the doctor, “Is this a death sentence?”

“No, of course not!”. All will be well

How did we cope? I think there was a kind of silent acceptance of reality. The hard thing was having to tell the girls. We sat them down. As well as the immediate shock the news impinges on their faith. Mothers are supposed to be invincible for goodness sake. So we tried to give them reassurance within the context of our shared faith.

(N) was due to go into (N) hospital for her lumpectomy but she had already developed abscesses under her arms from when the biopsy was going ahead and so because the abscesses had to be cleared up first, the operation had to be delayed. After the operation, the lumps they removed were definitely malignant so a full mastectomy was arranged for four weeks later. We both said a ceremonial goodbye to her boobs. We knew we were upheld in prayer from the congregation. I remember walking off down the corridor and saying prayers for an hour or more. We were confident that things would be sorted out. We had faith in the fact that we were not alone. We very much hung on to positive words.

After a period of 'recovery' from the operation (N) had chemotherapy for 4 – 5 months. Les was teaching through all of this. She was adamant that she

wanted to carry on through all of this. We had immense support from the church. Right from the word go we decided that we would share information with our church members. We were confident that all would be well. (N) recovered from chemo, she coped with the side effects and she was checked every three months. The signs were good, there was no hint of anything going wrong, until the end of May 2004.

2. How did it develop?

(N) began to complain of a bad back and shoulders. She went to the doctors, the G.P.s verdict was that in all probability she had pulled a muscle. This was all around the time of our daughter (N)'s wedding. On the day of the wedding, (N) had pins and needles in her legs. We drove to the church. (N) found it increasingly hard to walk. We got her into church. Half way through the service she lost the use of her legs. It was obvious to the congregation that something was seriously wrong. She had to be carried out of church at the end of the service. So **(**N) and I went to the hospital whilst the rest of the family went to the reception. (N) was now paralysed from the chest down. When we got to A&E at (N), no one seemed to know what to do. (N) needed a scan to see what needed to happen next but the radiographer on call refused to come out. One of the wedding guests was a senior radiographer from another hospital, (N) so I rang up the wedding reception to talk him. He couldn't come out himself as he had been drinking He contacted colleagues at his hospital in (N) and arranged for (N) to be transferred to there the following day. So (N) spent the night at the hospital where she was, (N). On

that Saturday night, there were no verbal prayers spoken between us. Words seemed out of place somehow. We both held hands and prayed independently. (N) was transferred to (N) the following morning. The scan showed that the cancer had spread to back bone, skeleton, skull and liver. On Sunday (N) and (N) and our other daughters came to (N) hospital to see (N). They were not due to go on honeymoon until the Monday. Everybody knew the score. Then (N) had to go back to her the first hospital at (N). We were still optimistic. The girls still felt their mother was invincible. After that, (N) began three months treatment at (N) Hospital. She attempted chemo but the side effects were too unpleasant. She lost skin from her lip. It was clear that the chemo not working. So what to do then?

3. Could you briefly describe the treatment plan? Was it subject to change?

It was decided not to continue the chemo. Then reality kicked in. We could actually lose (N). Then one thing after another seemed to go wrong. We initially hoped that life could return to (N)' legs but after a week nothing was happening. Then there was a battle to save her arms. One night, (N) spent a night in real turmoil, experiencing a dark night of the soul. - “But I'm alright now.” I can remember thinking “What the hell is happening here?” I remember one thing where (N) asked a nurse to turn her over. The nurse said “Turn yourself!”. Even if the nurse did not know how ill (N) was, that was just out of order. What you long for is that you just want things to be normal. And another thing, (N) was hoisted into the bath. She loved that bath. She was left in the bath for three hours! There was no change in (N) over the

three months. We seemed to do an awful lot of waiting with nobody suggesting anything at all. Then Social services began talking about getting (N)home. One of the men who came to see (N) warned us that you will to have to stand up for your rights and battle for everything. (N) was really very upset at this, at being such a burden. (N) then got MRSA on her arm. It was bandaged up. Three days later it was still bandaged up! The bandage had not been changed. When we queried this, a doctor told us that he had put in a request for some treatment to take place. His response to why it clearly hadn't ocurred, was to shrug his arms and say “What do you expect?”

So we found that our faith in doctors and nursing staff was severely shaken. It seemed that we were up against human fallibility all the time. BUT, a couple of NA's were truly outstanding. It was they that got (N) through these three months. They represented normality in the midst of chaos They organised wheelchairs so that I could take (N) out and be normal. Also one of the chaplains at (N)'s, (N), turned out to have been one of my old curates and so was therefore known to (N). He brought (N) a hand held wooden cross. This gave her something to hang on to through the night. It became a very important symbol.

Another clergyman, a senior cleric within the diocese, visited (N) and said “Are you alright with Jesus?” (N) said to me, “Sort that guy out, he seriously needs to discover a bedside manner!” (N) was visited by the bishop, the

archdeacon, the rural dean and the chaplain. It was clear to the patients that (N) was a woman of faith. This gave them permission to talk about their faith to (N). Typical of (N), the hand held crosses which she received herself, she gave to patients who drew great comfort from holding them.

After three months in (N)'s Hospital, (N) was moved to the (N) Hospice. There was a very real fear for us both that this was where people came to die. But it turned out to be a turning point, a revelation. Whilst (N) had been in hospital she seemed to be for ever having blood tests to measure blood sugar levels. These all stopped. Then the chef turns up and asks what (N) would like to eat. “You can eat anything you like”. (N) plumped for a cooked breakfast. The joy of a cooked breakfast. The joy also of the drinks trolley and of sharing the gift of a friend's bottle of vintage port. ((N) and I drank this over two nights). From that moment, (N) was a changed lady. It was seen that (N) was not dying imminently and so she could be moved back to (N), closer to where we were living. A new phase in our lives began. Three months at the local hospice … then three months of normality at home. As it happened, there was no 'battling for rights'. I was even able to buy a disability vehicle which was paid for by the generosity of others. God was showing his care through the love of others.

4. What were your feelings after diagnosis prior to your wife's illness developing?

We all assumed that (N) would get better, we just did. I came into the church via an evangelical charismatic route. Prayer was central to this. It just never occurred to me at first that (N) would not recover.

5. As you think back from this moment in time, have those feelings changed in any way? If they have, could you tell me how?

Well, I definitely felt anger at the radiographer and the doctor. I remember feeling an incredible frustration at the time, a feeling of utter helplessness. As Les' illness progressed, there was a changed expectation of recovery. When someone close to you has not recovered from an illness, you need a person that does recover from an illness to restore your faith in the possibility of recovery.

I would now like to focus on how you feel your bereavement has affected other people's perception of you.

6. Did you make a decision to go public about your wife's illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

We were quite open with family and the church family to a certain extent. And senior colleagues within the diocese knew and the wider diocesan family as well. Perhaps this has something to do with preserving a sense of normality. When (N) was so poorly at home, those who visited the house

would come and see (N) as well. And (N) would come with me when I visited churches to preach.

7. Did you find that her illness and subsequent death affected the way that family, friends and colleagues related to you?

There's a real mixture here. You realise you are 'touchy', I knew that I was touchy. After (N) had died, when people would say to me, words very kindly meant I'm sure, things like “Do you know you are in bereavement?” I want to respond “Of course I bloody do!” I had a very short fuse. The reality is that people who are not going through bereavement themselves are on the other side of the fence and are trying to help from there. Then some people didn't want to talk about it at all but there was less of this from friends and members of the congregation. Then there was (N)'s involvement with the school. They had a quiet room for the children to go when they were feeling upset where they would write beautiful pieces of work that were stuck on the wall. “The trunk upstairs is full of these.” But by and large people's reaction to me and the children has been totally open. The girls reaction to their mothers illness and subsequent death has been one of utter shock. They didn't want to talk about mum's illness and especially not about dying. We were all there around the bedside when (N) was dying, a kind of last supper, our six daughters and their partners. In the final moments there was a sense of just 'loving loss'. It has bound the girls together with a what I can only describe as a kind of ferocity. Two or our daughters delayed careers to look after their mother. Let me give you an example. Last Thursday two daughters went out

for a walk together. The others that lived nearby, not the one who lives in London, heard about this and just had to come too. The girls talk a lot together. But none of us are able yet to talk about the death scene. They don't look at pictures of their mother that were taken when she was ill. When I think of her, I remember her, I have pictures of (N) before she was ill.

8. What have been the main sources of support to you during this time of bereavement? Was there any support that was especially helpful in your worst moments?

Without doubt, my biggest support has been that of the immediate family. Also, the knowledge that people offered their help and really were willing to help. I was offered bereavement counselling from the hospice. But I was bereaved from the moment of (N)'s diagnosis. I think I did a lot of my grieving before (N) died. But it was important to know that support was there. I felt very supported by my colleagues who'd shared the journey with me. I particularly valued their practical support and understanding. They encouraged me and enabled me to be gentle with my work timetable not making too many demands upon me. And the prayer support was absolutely crucial. Then there were the meals turning up on the doorstep. I was particularly touched by a number of newcomers to church responding with help. And meeting a mate, (N), (N)'s mother, whilst still in bereavement. It's strange isn't it, that if (N) hadn't been rushed into hospital, I should have walked down the aisle with (N) at the end of this wedding. I think her divorce came through the day of the wedding. Some people have welcomed me

marrying (N), others have seen this as a hindrance. They can't understand how this could have happened so soon. My daughters have found this hard but in the end they have been so supportive. So it's been an odd journey, a gradual journey. So now it's (N) and the girls and me finding my feet. I know I would be a different person in bereavement without her. I don't know how I would have coped.

I would now like to ask you how you regard the significance of your bereavement and its impact upon the world.

9. Did you feel that your bereavement had an effect on your relationship with others who are bereaved, both in your public role and your private encounters?

I realised that I was utterly 'naff' at giving advice to funeral families. You have to 'walk the walk'. You cannot stand in somebody else's shoes. Each person works through their bereavement in their own particular way. So I think I am less confident. What I want to do is give other people permission to tell the truth, to tell their story as they see it. Being 'in the same boat' does not mean knowing the answer to other people's bereavement dilemmas. It's possible that I might feel differently as a parish priest to how I feel now as a (N) because I don't take so many funerals. People think that I will have more insight, but the reality is that more and more I come to realise the inability of words to communicate the deep experiences of life. In two funerals that I have taken since (N) died, I have not done funeral homilies. I got the

congregation to say what they remembered about the person who had died. I first used this approach of congregational participation when I had to take the memorial service of previous incumbent who had proved unpopular with many and who had divided the parish. His funeral was elsewhere, and I found myself having to invent a liturgy for dealing with this, people's anger, guilt and the like.

10. Has your bereavement changed your sense of priorities? Has it caused you to make any major changes in your life?

One thing that's changed is my attitude towards longevity. I married (N) last year. One of my daughters acted as my 'best man'. For me there's been a realisation of my own mortality which affects everything. There is an immediacy to life. I'm just so aware of the danger of wasting time. I guess a major bereavement leaves you with a legacy of the fear of bad news, it leaves you on edge about life changing points. You want good news all the time. For example, (N) has just been for her regular mammogram. I was on edge the whole time. Waiting. I have a totally different world view. Earlier this year, (N) and I went on a Caribbean Cruise. We could have gone next year but why wait. Anything could happen. It has changed the way I work too.

11. In the context of your wife's illness and subsequent death, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

When you've been through something like this your faith can no longer be naïve. I'm aware of the fallibility of doctors now. I came to faith via a charismatic route where if people from the congregation were sick, we would lay hands on them. My faith has now had to become more grounded in the reality of how it feels when the person you love does not get better. I've had to face up to the fact that God works through medics as well as through miracles. Theologically, I think I have a greater appreciation of what God achieved through suffering and death. But forgetting my own faith for a moment, I've been so struck with seeing how faith helped (N). The comfort she drew from the cross in her hand.

I think too I've become less religious. At times it was clear that words and prayers were not necessary, indeed they could possibly a hindrance at times. My prayer life is more simple. At the moment I'm wondering what is the point of fixed liturgy. Maybe in time I will journey back to that. Then there's the questioning why you do things the importance of resting with your faith rather than running with it. And I've become intolerant of religiousity.

12. When thinking of your experience of bereavement within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

Well it's back to the 'Footprints' poem really. Not just since Les died in bereavement but throughout her illness as well. Just knowing the reality of

not being alone. Then there's the whole matter of timing. You know, why did our daughter (N) not arrange to go on honeymoon immediately? Then there was the chaplain (N) known to us both from when he was my curate accompanying Les, the right person, being there at that crucial time. The importance of the hand held cross that he gave (N). So important to (N) through the dark night of the soul, through those nights when she couldn't sleep. And simply getting our support vehicle and having three months of normality at home. God was in all of that. Looking back at the blessings. Our daughter who had just sat her A levels, delaying going up to university. She watched endless episodes of 'The Forsyte Saga' with her mum. When she went up to university, she changed her degree to Theology. I believe she will offer herself for ministry at some point. And she would be brilliant too. Seeing God's hand in all of this.

13. Would you say that on balance you have been able to see your bereavement in a positive, a negative or a neutral light?

On the negative side, I've lost a loved one, the person that I have shared my ministry with. Seeing tears in my daughters' eyes, heartbreaking, something no parent ever wants to see. Then the six grandchildren, all born in the last two and a half years, all born since she died, that (N) will never see.

On the positive side, there's come an enjoyment of time and of life, of every moment. There's been a binding together of the family. There is less

attachment for me to material things. But the material things I have become more attached to are those that represent treasured memories.

14. How do you feel about the future?

I'm a bit more sceptical about medical care and much more optimistic about Hospice Care. I'm cynical about chemotherapy. Did it or did it not work for (N)? Was it worth putting (N) through it that second time around, and for what? I appreciate my day off more. I am not so inclined to be a workaholic. I have a colleague who is just that. If I hadn't met (N), perhaps I would be too. Who knows? The importance of holding life in balance.

Thank you very much for agreeing to be interviewed.

Taped Transcription 003.

I would like to begin by asking you about your illness:

1 Could you say something about the onset of your illness. How did you first become aware that you were unwell?

This was in 2001 when this all came to a head really. And I'd not been feeling well for quite a while. But I put it down to just the pace of life really. Trying to be all things to all people. Busy job, mother of teenage children, vice chairman of the College, all of those sorts of things going on. And I'd been to my GP complaining of some symptoms, but she rather pooh poohed them and put them down to my age the fact that I was female etc. but then some colleagues told me how pale I looked -it was at the pantomime in fact- doing the sort of safety announcements. But you know they kept telling me how pale I looked. And “Had I had a blood test or anything” and I said no. And I went back to the GP under duress from these two colleagues. And she wanted me to have a blood test and some other tests done. And it seemed strange looking back on it now. I can remember getting my diary and taking my diary home to work out when I would be home early enough to start 14 hours preparation in order to get in the next morning to have a blood test. You do have to wonder what all that was about .

So I eventually got the tests done and handed them in to the Path. Lab and then went off the Philippines for a week to recruit new members of staff. I

got back from the Philippines and my husband said that the GP had been on the phone about my test results. And I said, “That was nice of her” because we knew her because her son was friendly with ours, so I just thought that she was being helpful. Anyway, I had a day off to recover from the flight and went to the surgery and she told me that I didn't have Diabetes, my cholesterol was alright, And you know there's a 'But' coming, don't you. But my haemoglobin was 8.9 so I was just on transfusion level. And that my – what was the other test I'd done, I'd done another test- blood in stools was plus, plus, plus. So I knew I was in trouble.

So she said to me then who I might like to see at the hospital. So there was no choice for me . I just said which surgeon I wanted to see, really and if she'd care to write the letter now I could take it with me. (*Laughter) You know.* And I went home, I had the rest of the day off. I went home, and one of the colleagues who had been pressing me to get sorted out was married to the surgeon I needed to see. And I phoned her up and I said “Well I'm in trouble”. Anyway, she said she would get me seen as soon as she could. In fact (N) saw me that afternoon. I got a phone call back saying “He would see you at 4 pm”. So bless him, I mean I wasn't looking for that (kind of treatment) but it was fantastic, But the bad news was at 6pm that day I knew I had a serious problem.

Then on the Friday of that week they brought me in for an endoscopy and by 2pm on the Friday afternoon, I knew that I had cancer, I just didn't know how bad. I got sent to X ray and when (N) told the radiologist who I was., the radiologist stayed on. So I went down to have a scan and X ray, and the

radiologists couldn't meet my eyes at all And I suddenly realised I'd been in the service 20 odd years. I'd been a medical secretary. I'd sent people for all sorts of tests if you like, you know, talked to all sorts of people. I suddenly realised they were looking for more. And that was a very scary moment. So that's a kind of precis.

2. How did it develop?

I think it had been going on for some time, and as I say, my lack of interest in myself if you like, or my time for myself … It's funny, because a few weeks before all of this blew up, as I've just described it, my husband insisted that I went out on a bike ride - it was an organised one. And, I'm a fair weather cyclist, you know, and I hate hills, and he's a mad keen cyclist and he loves hills. But I agreed to go out with him, and I cycled 16 miles. And I just felt awful afterwards. I collapsed in a heap on the sofa and he said “If you are so unfit and fat” and all the rest of it. So a few weeks later I was able to say, “Actually (N) I was ill!” And it was just like Spike Milligan you know, “I told you I wasn't well!” So it really was a kind of a wake up.

How did it develop? Well as soon as they knew that I was in this level of trouble, (N) said he'd have to do surgery on me. Ow! And so I was booked in for an operation. Basically I was going to loose a large chunk of my bowel and we hoped I would be all right after that. Depending on the result from the pathology on the bowel would depend on what happened next. And that was scheduled for about two and a half weeks later I think. What was interesting

about that was I think I got different treatment because of who I am in the organisation. Now what do I mean by that? I mean things were said to me that would not normally be said to 'Jo Public'. So (N) kept saying he felt sure it would be OK, it would be an early stage disease and I would be alright. He kept saying this. I kept thinking I don't know that I feel that certain about it, and I couldn't allow myself to buy into his optimism. I also thought that his optimism might be this was what he thought I needed to hear. And so I came in and had the surgery. I was warned I might need to have well, either a temporary or a permanent colostomy. At the end of the day I didn't need either. You know, you suddenly find yourself where you've never been before. I'd had two caesarians when I had my children but that was my limit of personal experience of being hospitalised. I'd seen other people go through an awful lot, either because I worked here or, you know, by that stage I'd lost both my parents, one of them to cancer, so I wasn't a stranger to kind of people being ill but it had never happened to somebody close to me in that sense, you know, or someone even my age because then of course, I was only 48 and that was extremely young to be diagnosed with bowel cancer. Typically, it is in the over 60s so.. luck of the draw because No history of it in the family at all, no history of anything like that in the family. And so I had the surgery, and (N) sort of being optimistic, and then he came into the room and said that he'd.... I wasn't expecting the results. Of course the other thing they'd done was they'd hurried up the results for me. So I knew the results should come eight days after surgery, and they came seven days after surgery. And they came on September 11th 2001, which is the day the towers were hit. So he came in and said that in fact the result was a ' C '..

Oh and the other thing I learned was when a consultant comes into the room with a nurse consultant, then you know you're in trouble. It's alright if they come in on their own, its not alright if they come in with somebody. - somebody riding shotgun! It must have been very difficult for him you know because he's known me for a number of years. I just saw his struggle. So he'd said, I had a ' C '; and my response was “Well I've never had an 'A' for anything and I didn't expect to die with cancer. So, you know. I couldn't... The bit with my family in this kind of time, I just told my sons, one was 20 one was 18, I just said to my sons.... they knew I was ill.... After the endoscopy I said well I've got to have major surgery, and I've probably got cancer but we don't know how bad it is, they were a bit...

It's interesting afterwards I spoke to someone who was employing my son and she'd said he'd arrived at her house, he slumped into the chair, and she's said “Oh what's up with you then?” And he just said “Mum's got cancer.” She was kind of... and that's his way of dealing with it. My younger son bottled everything, and I'll probably come back to that a bit later.

And it was very difficult to tell friends, It was that strange thing and... Oh, when (N) gave me my result, I couldn't tell my husband. He was due in to visit me And I kept saying, “ I can't tell him, I can't tell him.” I just can't do this. And so I made (N) stay on the ward and head (N) off and talk to him. Because I just felt I can't say this to him. And, you know. I can remember nights between the endoscopy and the surgery when we just … It wasn't so much what we said but what we did, and so we lay in bed clinging on to each other. There was just a safety in that really and sometimes we sort of talked

and you just didn't know.. but what can you say? You just did'nt know where you were. And until I knew … ' C ' was bad, ' C ' was not good. I later found out that my prognosis was 39% survival over five years. That was not a good place It was better than being a 'D ', but that was not a good place. And then I knew that I would be facing chemo. as well. You know, no two ways about it.

The other weird thing was phoning people up and telling them. At the point that I had the endoscopy, I thought I'd better start saying to people that I'm going into hospital now. And you know, not too sure what the result would be. And it was like when you have to tell somebody about a bereavement. And the first couple of people you tell you are very stumbly and almost tearful, and then you get the hang of the script. And then you find it much easier to say to people what it is because you are starting to exert a level of control. And you know what you are going to say. You don't want to be interrupted. You don't want people to mess around with you when you've told them . It was the same sort of feeling as when I told people that my mother had died or my father had died. That kind of... ooh, I just to to get this thing out. And when I was telling the third person, I thought I'm alright now, I've got the hang of this, I know what I have to say.

3 Could you briefly describe the treatment plan? Was it subject to change?

Well it was the surgery and then they said I would have to have six months of chemotherapy. And at that point I thought, “Right”. I came home from

hospital. I knew I would be coming in to see the oncologist (N). But I thought I wondered what the treatments are for this. I knew something about cancer because I had written the cancer plan to make (N) a cancer centre years before, so it all came back. My mother had had a best friend called (N). They had grown up together in Ireland and had come to England together. And (N)'s daughter, (N) is older than me, by that I mean four or five year's older. I was like 'tail end Charlie' at the arrival of all the children. I had no siblings. I was a much loved and wanted child of older parents but people like Margaret were there as I was growing up. It's only as we became even older adults if you like that she began to realise I was not this kid any more, you know. So we began to get something going between us. But she'd been diagnosed with bowel cancer about 18 months before me. But her prognosis was much worse than mine. But I phoned (N) and she was talking to me of all the treatment options that are around. She talked to me about this drug call Ariditiken Which is the best.. The typical treatment is 5FU, the next one is Ariditiken And Ariditiken was being used in Europe. So I looked on the web, and it seemed to be the drug you would ask for. So I went and asked the oncologist when I saw him if I could have Ariditiken (?) And he said, "No because I wasn't ill enough". In other words, my liver or other organs weren't involved. But the good news was there was a clinical trial. And I might get Ariditiken and 5FU in combination or just the 5FU. He put me forward for the clinical trial and I got the combination drug. Interestingly, when you go for a clinical trial, they put you through a whole load more tests. Basically they want to make sure that you are reasonably well, that you don't die and bugger up the numbers. But seriously, if I'd have had anything else wrong,

they wouldn't have put me in the trial. An interesting place to find yourself really. And of course you are treated like everybody else. When my data went forward for the trial, I was just a number. I might not have got it. People were just.. everybody was apologetic, you know, so sorry to find me in this situation. And I know the other really weird thing I got told afterwards was.. there were a couple of things. There was a lot of rumour in the hospital about what was wrong with me. People thought I'd had a breakdown. And so I felt obliged to put something into the newsletter, that I was going into hospital for major surgery, and I gather that the organisation felt a bit rocked by it, because I was there one minute and gone the next. And I was told afterwards people felt 'Wow'. I felt for my colleagues really. It manifested itself in care and that sort of thing, but it manifested itself in difficult ways too. Everybody thought I was kind of, you know... I think about an hour after I had been told I'd got cancer, the chairman was at the door wanting to see me because he hadn't seen me. I felt if he's come down.. you felt obliged to see some people sometimes, but um. Interestingly they discharged me after a fortnight and I picked up some kind of infection and I came back in. And we told nobody that I was back in hospital, so nobody knew I had a third week in hospital. And we just kept the door shut. And actually, I felt worse in that week than in the previous two weeks. Because I was actually ill. The recovery from the op. wasn't a big deal – major surgery, but everything went according to plan. Then I picked up something and I actually felt low and ill. Anyway, they didn't have my name on the ward, they didn't have my name on the door. Nobody knew I had come back. A couple of people I told I was in, and nobody else knew. Because I'd had enough by then.

4. *What were your feelings after diagnosis prior to the illness developing?*

I was scared. I was scared about the diagnosis because it was such a serious one. You know, I haven't got away with it really. And I found myself in this position and even several years down the line I occasionally find myself thinking, “Good God, fancy being in that situation. Fancy being that ill, and you didn't know and ...” And I was desperate for my children. Just “O God, they don't need this.” How were they and my husband You know, you just didn't know which way to turn. Typical I suppose, seven eighths Irish and I remember thinking “If my mother was alive, this would have killed her!” That sort of thought... I was actually glad that both my parents had passed on and weren't having to cope with me being this ill. There was that, and then this friend of mine, (N) died the night before I started chemotherapy. So I went into that just terrified about what might happen to me. And I was going in to what was unknown territory for me. And I also thought, O.K. I had this illness and I had to have chemo, but I was going to be able to work part time. You know, I didn't see myself as being 'sick'**.** And then when I had the chemo, I was knocked 'six ways sideways'. It was beyond belief, I had every side effect going. And I had some they hadn't even thought of! *(Laughter)* And I can remember the day they said (I had been colouring my hair up to that point , oh because it was quite grey)... And they said “Oh you can't colour your hair when you're on chemo,” and I thought “Jesus, how much worse does it get?” I have to say, I've always had a good sense of humour through all of this but.. and it has been necessary. And I did find every which way to

laugh at this. I complained about being the fat cancer patient, I lost no weight at all through having cancer! I was just the fat cancer patient. And I get told to be quiet by the nurses. That wasn't the thing to say. I did find several ways to laugh at what was going on. I said to one of the surgeons I don't know why they just didn't do lyposuction while I was there. He said, “The industrial hoover had been out that day!” *(Laughter)*

5. As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?

Well I think they have as time went on. I can remember not allowing myself to think that I'd make it until I was three years down the line. It was only then. I can remember coming out the (N) Hospital standing... I used to go for my check ups and Id come out onto the forecourt and I'd call for a taxi to get me back to the (N). And in the time that I was waiting I'd phone my husband, my sons and my sister in law and tell them I was alright. And I was always alright. And I was three years down the line when I began to feel I can allow myself to think I'd get to five years and then on. And that was a real.. it was one of those moments, one of those exhilarating moments in your life when you suddenly kind of think, “Actually, I think I'm in quite a good place now.” And when you think I'd been back to work within eighteen months or two years of that time, I've never really thought I was over it or fully recovered from it in any sense really which was astonishing when I now look back on it. And when I got to the five years, that was the moment when he said to me, “I don't need to see you any more”. He countered that with “I can't use the word

'cure' I can only use the 'remission'! So you know you're living, and people will use that term so carelessly. They don't know what effect it has. I think, unless you're in that situation, you don't know what effect it has on people. It's a horrible word. “I'll never be cured of cancer, I will only ever be in remission!” I've been in remission now for eight or seven years, I suppose. And I might have another forty years. And I will only ever be in remission. It's just kind of there. If you ever talk to a doctor they will say You are still in remission.” You know, I am! No understanding of the psychological effect., none, absolutely none. When he told me I was being discharged, that was the moment when I had... “Right , that's fantastic!” I almost skipped out of the clinic. I said to the receptionist, “I don't have to come back here again.” And I just felt 'over the moon', I can't describe it. I phoned up everybody . I said, “That's it . And I did something I've so rarely done in the whole of my life On the boat coming home I thought, “when I go home, I'm going to have the biggest bloody gin and tonic I can find”. And I went into the supermarket , I knew we had a gin, so I bought the tonic and I bought the lemon, and I didn't just have a little glass, I poured a long glass. I was on my own. (N) must have been out, or at work or something, and I had the longest bloody gin and tonic I have ever had in my life. It felt fabulous! You couldn't take that moment away from me. I didn't have to go back and worry about the six month blood test and sit in his chair and wait while he got the result and told me whether I was alright or not. I was like walking on cloud nine for a couple of days after that telling anybody who would....Even the taxi driver who said “You look really happy,” and I said “I've just been told I'm clear of cancer.”

And he went “Oh, that's really great” But he didn't give me a free ride, but he was really happy for me.

Weird things happen to you you know. While you are in treatment, in chemo, maybe not radiotherapy because you are only on that for six weeks. When you are in chemo, you're going through it with a bunch of people. Every fortnight, on a Monday morning, you go to (N) and you have your blood test, and you end up sitting in the same room with the same group of people. Only then one of them's not there. Or one of them comes over and says “I'm not having treatment today. They've decided there's nothing more that they can do”. Your feeling is “I'm sitting here listening to people who are telling me they're going to die”. Oh shit, it could be me. You're glad it's not you and then you feel “Oh that's bad” and that's a little bit of survivors guilt spouting. It's a really weird place to find yourself. One minute you are in the land of the living, and then you are in the land of the people who might live if they're lucky! And whether you are like me, with a background in the NHS or not, nothing prepares you for that, you know. It was just aweful, aweful. People were there and then they were not. I can remember coming into the hospital Its a strange journey. I can remember coming into the hospital on a regular basis. I used to have my treatment in (N) because I was on the clinical trial, coming here.. I had a Hickman line in my chest. (I finally managed to find a use for my cleavage!) *(Laughter)* I used to come in and get the line cleaned out. Walking down the corridor, you know you're in civvies you've got your coat on, and it would be amazing how many people would ignore me. Well, they try and ignore me. And I used to play a game. I'll let them nearly get by and I'd say “Oh hello” And it's that bit about how we ignore people in the

corridor. We're not engaging at all with patients or the public. Walking down that central corridor is a kind of acid test, it really was. One close colleague walked right by me and I thought, “Yea, I've become one of the invisible ones. You don't want to eyeball a patient because they might ask you something. It was fascinating being on the receiving end, wherever you were. Lots of laughter about it. I was on my first treatment in (N) and I reacted so violently to this drug every time that they gave it to me. I was always on the anti-sickness tablet. But the first evening I was in Southampton, I threw up all over the nurses station. By the time I got back to the (N), the nurses here said, “Gather you've been misbehaving yourself then!” *(Laughter)* There was this kind of “ Oh all right OK then.” There was a bit of fun to be had about it I suppose. And I suppose just thinking about my family and everything. I don't know whether I am answering some of your questions.

My boys were... (N) went back to college in September and (N) started university and (N) used to appear on the doorstep. He was in Bournemouth. He used to appear on the doorstep every two or three weeks, and I think it was his way of …. he's my eldest, he needed to make sure his mother was still there, I think. And he'd just kind of say ‘oh there wasn't too much going on for the next couple of days, so I thought I'd just come home’. And (N) was in (N) doing his first year, and he dropped out at the end of that year and... this played a big part in it. He really couldn't.. he just wanted to know that I was OK. I could talk to Alex about how I felt, and what was happening to me, I could never really have that... but Ben was nearly two years younger and

only18 for goodness sake, he wanted to know that I was OK I was quite glad that they weren't at home. I was ill most of that nine months. The medication played havoc with my body. I lost a lot of my hair, I couldn't concentrate, I was often ill, physically ill, My husband used to have to, - forty years before you would expect him to - would have to dry me after a shower and have to sort me out. It was just, you know kind of bad. I'm glad they weren't there to see the worst of it. And when they were, I could usually put something on for a couple of days. I looked kind of OK and was well for them. But I was glad they weren't around to see the worst of it. Yea, it was awful. And they needed to know. They needed phone calls from me. Because on the Monday night I had my chemo, they needed to know. They wanted me to phone them both to say how I was doing. And one of the nights I phoned them was my eldest's 21st birthday. And you just kind of thought, “Well, 21 years ago, I didn't think I would find myself in bed having chemo on his birthday. So it was moments like that really And even now eight years down the line, I can tell you every day... the date of every time I had a chemotherapy. It's carved. I think it was emphasised for me by being in the NHS. There was never any getting away from it. I came back, and an issue came up one day and a colleague said You've done this, how was it for you?” I said “I didn't think I was here to give my experiences as a patient!” I was seething, I was inwardly thinking “How dare you cross that boundary.” Because in me it manifested itself in you lose control completely when you're in this situation. You don't know what's going to happen. No matter what treatment you have, one lanky little cell can do for you, you know. People write about fighting the battle with cancer. I don't agree with it. I don't agree, because there is no battle to be fought, because

you've lost. You've lost from day one. You've either won from day one or you've lost from day one. Do you get what I mean? I could not write about... I've personally....I have said to (N) “Don't ever say I've fought a battle with cancer.” Because actually, if the cancer is there, it's won. It's only a matter of how long you put it off for. That's my take on it, it is not a battle. There's no way you can win with some cancers. You can put it off, but you can't win the battle.

The other thing I said to people, if I die, I don't want any trees or benches. I've been sat on, shat on all my life. Do you know, it brings all sorts of things home to you. We bought a house in France as a result of everything that happened. One of the positives was, we always thought that when we retired, we'd buy a house in France. Well, yea, what was that about? And so we got on and bought the house in France**,** and it was the best thing we've ever done. It's been an absolute godsend to us over the last few years. If I see something in the paper about an exhibition or a show somewhere, I kind of think well... yea we're going to go to that. Who knows?

I would now like to focus on how you feel your illness has affected other people's perception of you..

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

Well I've sort of answered that, about the fact that people were saying I'd gone off with a nervous breakdown, because the job had been too much. And I just thought no, I'll front this one and tell them what's going on.

7. Did you find that your illness affected the way that family, friends and colleagues related to you?

Well I think I've covered that point as well. But there were also the people you'd meet, maybe you didn't know them very well you didn't meet them very often. And when you met them, they'd come up to you, and their head would go slightly to one side, and they'd have a caring look come over them and they'd say, "(N), how *ARE* you?" And I'd think.... and I said to my husband one of these days I'm just going to say that I'm terminal, because we're all terminal, and the end's going to come some time. And I got so fed up with this "Oh (N), how *ARE* you?" What did they expect me to say? So, you know. But there was a certain person, not people who were close to me, it was generally people you would bump into in the street. who would be guilty of that.

8. What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?

I'd have to say my husband was absolutely fantastic because he'd just... he was always.... no matter how down I felt he would always be doing the … you've had four treatments, you've had five treatments, he would always be positive in that sense when I felt ill. He and my eldest son always thought I'd.. we'd get through it, that I would not be dying with this. Always positive.

Certain friends were very positive with me . Once or twice though, people would not allow me the privilege of feeling low if you like. And that was equally important to me as to be 'jollied along' sometimes. I have a faith, I'm Catholic, cradle Catholic. And I've had a bad time. I've not been going to church for a while. But I got back to church about a year to 18 months before all this hit the fan. And that was very strange because I was on the prayer list while I was in hospital. Then I disappeared off the prayer list and never went back on it really. It was just odd because I'd pitch up, barely able to walk in to the pews sometimes or get Communion, you know, and just kind of never made it on to the list. My priest at that time kept saying “Oh when you're ready let me know and I'll come round”. And I thought, “Why don't you just tell me when you are coming? Why don't you just say when you are coming?” So I never got a visit from the priest at the church where I was attending. And the priest in my local town who knew me quite well turned up once .A friend then turned up and he (the priest) ran away like a frightened rabbit. I think he was quite glad to get out really. So I have to say from my own faith, very little support. Interestingly though, one of the people I had met here as one of the hospital chaplains was in my house every fortnight to make sure I was alright. 'never let me go after that. He was in regular contact until he died. So I got more support from (N) even on a spiritual level, than I got from my own faith really. The only thing I would say for my own faith was One of the... I can never remember (you'll have to fill in the gaps (N)) it's.. I think it's Psalm 92. and it's about “and he will not let you fall” and “he will hold you in the palm of his hands”. It wasn't the words of the psalm that I liked but there's a hymn that been taken from that psalm**.** “And he will bear you up on

eagle's wings, not let the fowler snare you ” you know. If you read that hymn, that was sort of with me all the time that I was ill. And I got more comfort from that I think, than I did from anything else. I never bargained with God. You know when you are little, you make bargains don't you. If you get me out of this I promise I'll...Well I never did that. I never did that, I always thought, “Just give me a bit of dignity to get me through this. Don't let me down on that”. But, funnily enough, a couple of years ago, when my husband was admitted to Coronary Care and we didn't know quite what was going on, I bargained with God then. I just wanted him to let my husband get through this and be alright. And I would have given Him anything He'd wanted. So I just thought that that was interesting, it wasn't about me it was about him. And of course like all cancer patients, I've got a well planned funeral because I've had the time to think about it. And you do think about it. What hymns do I want, what readings would I want?

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

Yes, I talked about my cancer because I think we've all got stories to tell. People who are ill have stories to tell. It doesn't matter whether you are somebody with a heart condition, Parkinson's Disease , cancer, it affects you in your life in some way. In terms of cancer I felt that I had a story to tell, so

did others, but I was able to tell my story. And I suppose I was hoping if I spoke it would help others, and I think it has. I've spoken to cancer groups, I've spoken to non-cancer groups. I've got no problem... and I said it to a group of doctors yesterday So I've got no problem with saying “When I had chemo eight years ago”. But I need it to be on my terms. I can't... I find it difficult when I find myself in a situation where I'm having to deal with issues about cancer that maybe come on me as a surprise, you know. This interview is fine because I knew I was coming. I don't know. It's about sometimes being in meetings and you hear stuff, and you think, “Well, hang on a minute.” And sometimes I have let it play... I was with a group of doctors and they were talking about a particular test which they saw as a useful dignostic. And I said, “I don't agree with you.” As someone who's had that test on a regular basis, I wouldn't want you to send me for that test and you to get the result and... it's an indicator of how bad your cancer actually is . And I said “And you wouldn't know where that cancer was in me and neither would I so what help is it?” Don't go there. leave it. And actually, we've now got a consultant who won't allow G.P.s to ask for that test.

I've talked to the Cancer Forum here and I've talked to other groups, and I've talked to other groups of clinicians, you know, in my time. I did quite a bit of it at one time then thought, “No this is quite difficult now”, because it was like not getting away from it. But now it comes up, either because I chose to mention it or there's a long enough gap since the last time and I think “Oh I'm alright now.” So when you asked me to do it, it's ages since last talked about it.

10. Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?

I think the house in France, what we do, how we do it. I'm going to retire next year a couple of years early. Um, I think my reaction to people and my expectation of standards of care has risen. I can't be doing with poor care, I can't be doing with poor attitude. I have a deep respect for the Macmillan Nurses, especially (N) who looked after me with her dry kind of matter of fact way that she has. She's great.. I value my time with my children much more now. I don't have a lot of time for money in my life. When I talk to my children about this I say “Take it all, I don't want it!” I've been to Lourdes a couple of times. My faith now is not as strong as it once was. But I get something very deep out of my trips there. I help push wheelchairs when I'm there, I'm very hands on.

11. In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

I think I've covered this already.

12. When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that

time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

I do tell people that that time was a gift. Because.. I suppose you would describe it as a gift when you come out of it the other end and you're alright. Whether I'd have thought of it as much of a gift if I'd found myself dying from it, I'm not quite sure. I suspect it would have been a gift because it would have changed my outlook on life. Even for that time, it would have brought something to me. I think it was a gift. It has made me think about life differently, really value it more. It was a wake up call in a number of ways. Do I use any phase? No, apart from that hymn. I think that hymn gave me a feeling of safety, you know in terms of what it said. It's certainly one that when I've gone to Lourdes.... I was asked to give a reading and I've used that hymn because I've felt it's a hymn about safety, about faith and safety. It's about how you will be looked after. Just give yourself to Him and it will be alright, whatever 'alright' is in his view I took great comfort from those words They were about keeping you safe. There weren't really any other words or poetry or anything else that kicked in.

13. Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?

Positive, definitely positive. I don't think, I don't know, it would be interesting to see if people recovering from cancer see it in a neutral light. With a condition like this I expect they go one way or the other. It's had a huge

impact on me because I still live with the... I have problems with my diet. I'm on three yearly check ups still in the Endoscopy Unit. There's no getting away from it. But in a sense I kind of feel I am looked after. I hate to say it, but if anything is the matter with me, I only have to say but I've had cancer and everybody goes into overdrive to make sure I'm alright. It's weird isn't it. I get the flu vaccine because I'm in an 'at risk' group because I've had cancer. I did have cancer, and everybody goes “Oh, alright, OK...”

14. How do you feel about the future?

Oh positive. It's odd. I feel positive but, you know. If I had back ache for several days or a headache that didn't clear up, I'd go straight to “God, I hope nothing's come back!” I don't think when you've had something like that, you're quite so sanguine about life's aches and pains as you might be. You do immediately go to, “God I hope I haven't got secondaries.” And then you talk yourself out of it. “No you silly idiot, you were in the garden yesterday, and you lifted that wheelbarrow so no wonder your back is hurting. Come on, don't be daft,” and of course it is all right, isn't it?” Does that answer that question?

Thank you very much for agreeing to be interviewed.

Transcription 101

1. *Could you say something about your professional life as a musician. When did you first become aware that music was to play a pivotal role in your life?*

I think when I was very small and my paternal grandfather was the village dance band pianist in (N) in the (N) and my initial introduction to music was sitting on a double piano stool while he played Military two-steps. My favourite piece was the 'War March of the Priests' which he played from memory. He wanted his grand-daughter to be better than him by which he meant be able to read the dots more efficiently than him. He had a recording of Josie Itoni (?) playing the Chopin Fantasy Impromptu and it was that classical tradition in which he wanted his grand-daughter initiated and so somewhat sadly at seven I was taken away from dancing,- which I really loved but because of my size and shape was probably never going to get very far with (although I was an excellent tap-dancer), - to piano lessons.

So I went through,- my parents only had enough money for piano lessons and there were no chances of anything else, - so I went through all the grades and in the end, but much later Teacher's Diploma in piano. But in school I got free lessons on the cello in a class when I got to the Grammar school. My head teacher had aspirations for me to read Latin and Greek at Oxford but music was what I wanted to do. I think there was a measure of rebellion too against her as well, and so I went to Oxford and read music.

I was singing as well, singing in church choirs and singing in the church choir in (N) that had women in it (which was St. Mary's (N)), so that gave me the call, and singing solos. Actually I think I did have some singing lessons at the time.

I don't know whether I aspired to be a professional musician. I think that from the moment I set foot in school at 5 I wanted to teach and to a certain extent when I left Oxford. Although I did aspire to do a PhD, I didn't get the first that I needed. And I really kicked over the traces of Oxford, I mean, having embarked on a PGCE and instead of doing what a lot of the women did who read music at Oxford, to become head of music in a girls' public school or girls' grammar school. It was interesting really, the men knew they would go on to have careers as conductors and composers but we were scheduled for teaching really.

I loved the primary school teaching practice and went into the primary school sector for which I was ill prepared really, because although I had learnt to teach music in it, I had not learned to teach anything else. That gave me the chance to explore children as composers which was relatively innovative in the 1960s. I had been taught at Oxford that in order to compose you needed to be male, speak German and Italian and dead probably, and so I suppose I wanted to challenge that myth, and I did in the classrooms.

Looking back at it now I think it gave me chance to compose as well. Because I was composing, using material from other people. So those were the early days and I was involved in the church at that point in the folk worship scenario because I was working in Notting Hill just after the race riots and living in (N). And these were the days of 'Songs in the Square'. Sydney Carter was moving from a backstreet press in Soho into Stainer Bell and Galliard, publishing things like Lord of the Dance and being you know, revolutionary material and becoming main stream.

I even created material then, I actually arranged other peoples material. Then I got married and had children and continued working in the playgroup and that sort of area with children. And then (I) got quite depressed and it was in the depression that I wrote 25 piano pieces based on the writings of Julian of Norwich. And at that point I began to think that I really did want to compose, and that in fact, is what I did do. I was on quite a lot of medication at that point, and as soon as eventually I managed to wrestle myself out of the grasp of psychiatric medicine and medication, the first thing I did was write the text of the hymn, and once that medication was off, then the music just flowed out really, although it was discovered in the middle of the depression the marriage failed. I decided that my maiden name was (N) and my married name was (N). (N) of course (my maiden name) has a composing ancestry.

At that point I had to get a job in my own right because at that point I had lots of bits in Deal which..., and I had no idea how the bits would continue. I had a mortgage. So the job came up here and I changed my name to (NN), and in many ways that was the notion that the (N) would be the composing bit. I wanted that name back and I put it back quite deliberately. And then you know I went and saw, we had a princely sum of £250 worth of stock that we were offered from time to time here and I thought seriously about what I should do and that was when I spent it on going to (N) and took him some of my compositions, most of which were religious in nature and the first piano pieces were based on Julian of Norwich. They were either hymns or piano pieces based on religious ideas particularly Hildegard of Bingen. She was fairly crucial too.

Having finished my PhD in 1986 I then moved sideways to do some educational research and got taken up with music and spirituality and again Hildegard became my mentor. She was a women composer, probably the first women composer I knew in any detail. And so on, although one has to say that there were people like (N) who wrote pieces for the Associated Board exams. But other than that there weren't any.

So, but of course I was in a sense practicing as a professional musician in so far as I was teaching music in schools, teaching music privately and, also quite significantly for the future composing, conducting the Schools Music

Association in (N) So conducting large concerts with children and certainly at (N) Grammar School for girls where I did in fact become head of music before I married. After four years in primary schools I was conducting orchestras and choirs, and it was a school that did television and stuff in Westminster Abbey and such, so my conducting skills were, and the level of the ensembles, was good there.

But it’s here really, and relatively late in my life, that I have the confidence to call myself a composer. That took a long time and you know, I have been fortunate in that I have been allowed to conduct a professional orchestra which I thought was beyond me. And of course I have done, and developed the one person performances which are in a sense a mixture of professional and disciplinary work. So that's how the career panned out I suppose, so it wasn't a clear trajectory as is quite often true of the men. We weren't expected to do any of those things even though we sat alongside men in the lecture halls for whom this was the obvious trajectory.

(It really brings it into relief when you see that it is all these life experiences that are being affected by all this ridiculous attitude isn't it? [Interviewer.])

Well yes, but I mean, there were no role models, nothing, so the absence of role models, you know the subliminal message of Oxford was that you're not

the sort of person who can do it. And that is what Oxford..., I mean Oxford taught me lots of useful techniques like fugue and counter-point and things like this, but the most important message was that it taught me that I wasn't the sort of person who could do it.

2. What are some of the key world events that have had a deep effect upon you as a person and therefore as a musician?

I think Notting Hill was hugely significant for me. I came from rural England, the (N), my grand parents were there and so on and my Mother always aspired to be there. There was a sort of change in my life when I moved from the (N) to (N). Although by singing in St Mary's. I was in the poorest part of (N), the church itself was really a sort of city church. And although I did try and associate myself with the dock land area of (N), which is sad and was aware of the poverty, I then of course went to Oxford and met people who were richer than me. But when I came to Notting Hill and lived in (N) where I lived in a community when I was first in London, well all the time I was in London, until I married. Initially I went to the Anglican church, but then in the six months I was at (N), I'd spoken only to the verger and discovered that most people had titles, other than me.

At that point I was involved with (N) who was head of Christian Aid at that time. He was organising these big Christian Aid festivals called 'Songs in the Square' which is where this great out flowing of Folk song stuff. And

suddenly I realised that song, it was the height of the protest song, could say something about poverty, about racism. And then some of the songs came from Notting Hill where (N), (N) and (N) were a team ministry there and their wives. And I went to Notting Hill and I still think in traveling the world, I never saw the poverty that I saw in Notting Hill.

I worshipped with the Methodists**,** I became a baptism role visitor, and I saw walls where the plaster was coming away and the woman said to me “There's nothing to keep the rats out”. And of course I encountered the racial tension of Notting Hill and was there when the Notting Hill carnival was born out of that in that area. So the experience of poverty and the racial tensions. I wasn't there when the race riots happened but it was pretty close after it, 1966 and part of that. So that was very crucial and I think that any child brought up in that period, there was that huge dichotomy between Flower Power and the Beetles and Love and all that. I never got involved in that area because my mother was relatively controlling and would have not liked me to have been part of that and I hadn't really found a way of rebelling.

But also I think the shadow of the invention of the Atom bomb and so on fell over our lives, and quite a lot of my contemporaries at Oxford chose not to have any children because there was a sense that it would be the end of the world at some point. So that debate about the potential that human beings had in their hands to destroy everything, which was a new phenomenon

really, for humankind had never before had the ability to match to it, I think that had a huge affect on me really.

So those two world events. And I think now it's the dilemma of the faiths, the faiths tearing one another apart, and the religious and spiritual aspects of warfare which concern me, have affected what I do. I am almost totally taken up now with how do we achieve forgiveness? How do we achieve reconciliation? Both at a personal level and at a cultural level. And I think that I am very taken up with music's role that it can play in that really. So I think it's the Holy Wars. It's in one of the songs of Sydney Carter that I think he puts it heavily:

“The Devil wore a crucifix, the Christians they are right

The Devil said now let us burn a heretic tonight

And then he wore a Swastika a Shamrock or a star.

The devil he can wear them all no matter what they are.

He'll beat a drum in China, he'll beat it in the West,

He'll beat a drum for anyone – a Holy War is best.

The Devil isn't down in hell or riding in the sky

The Devil's dead, I've heard it said, they're telling you a lie, they're telling you a lie.”

Still very powerful, I've never heard that before.

“Yes, the Devil wore a crucifix, the Christians they are right.

The devil said now let us burn a heretic tonight, a heretic tonight. “

He wrote a lot of incredible songs, 'The Crow on the Cradle' and so on. I think another one that is often not sung that I suppose exposes some of the dilemmas of Christianity for me and that was :

“It's God they ought to crucify instead of you and me,

I said unto the carpenter a hanging on the tree.”

And that was a hugely powerful song deleted from the American Forces prayer book because they thought it was too revolutionary, but it got people debating the significance of the crucifixion over their breakfast tables when we used it because I was the editor of (N) at that time. We used, well it was sent out in one of the assemblies books, so..., well all about suffering really, and the dilemma of suffering, I mean, and:

“God is in his heaven and he doesn't do a thing,

With a million angels watching and never move a wing.

God they ought to crucify instead of you and me,

I said unto the carpenter a hanging on the tree. “

Isn't that interesting?

“Barabbas is a killer and they let Barabbas go,

But you are being crucified for nothing here below.

And God is up in heaven and he doesn't do a thing,

With a million angels watching, they never move a wing.”

Incredible powerful stuff, incredibly powerful stuff.

3. *Who have been the key musical figures that have shaped your own musical development?*

Well Hildegard of Bingen of course, (N) who has encouraged my composing, Sydney Carter in the area of the protest songs and alongside him, (N) who

was (the) head of the Stainer, Bell and Galliard publishing who brought all of that lot into main stream publishing.

Of course I was brought up on the Classics and I am still on the classical cannon, I still use them. Who would I say? I mean Bach for its order, Mozart again for its order.

The Romantics, Tchaikovsky for his passion. Contemporary figures, Cage for engaging philosophy with music, quite important for me really. And influencing the piece, the latest piece where people are choosing what they sing and so on and so forth. The philosopher turned musician, so somehow or other the philosophy of the music, the philosophy could influence the structure of the music, I mean Cage is extraordinarily good at that.And I suppose as musical figures the English folk song still if one calls that a musical figure, Vaughn Williams' use in particular, I mean Vaughn Williams Folk Song Suites and all that, always transport me to something incredibly, you know. It reminds me of the rural sort of England, I've used folk song material in a lot of my stuff . So I suppose if that's a figure, then I suppose that music is quite important. Then of course the way that he used the English Hymnal, the way that the English hymn tradition has some of the finest hymn tunes of course. I mean did Luther say it or did William Booth say 'Why should the Devil have all the good tunes?'

4. *What have been those elements of your musical training that have proved of most use in the exercise of your professional musical life today? As well as being technically competent, what informs your ability to successfully interpret emotionally charged music, particularly that seeking to convey life's dark side?*

Well I suppose learning all of those techniques which people don't seem to learn anymore, how to write four part harmony, counterpoint and all of that stuff. I mean although it's not fashionable anymore I think a lot of technique needs to be done there.

I guess the ability to read the dots, although of course, I sort of rebelled against that. I suppose I want to be able to read the dots and to approach music orally which I think in many ways is recovering my grandfather's skill. I have long wished I could play much more by ear than I could. But there's no doubt about it that the ability to read the dots has opened up, if you are talking about the life's dark side, I think you're probably looking at people like Tchaikovsky and even Elgar and that sort of area where you've got um, those very dark sides really.

I suppose Beethoven, I didn't mention him, but I guess that he's got to be there somewhere. I think if one's talking about massive emotion, then one is

talking about the Romantics and two pieces which, I mean, people wouldn't say that they're particularly deep but there's a piece called 'Chanson Triste' by Tchaikovsky, um and then there's Elgar's ' Salut d'Amore' um and so on.

So the ability to access the Classical tradition, because I don't find the big emotions of that kind. I know they're there in the Rock tradition, but it's not my tradition, although I think that something like Sgt Pepper, which of course came out in the 60's, and you know I was quite interested in that. I know the Pop music did that better. I think there is quite a lot of it there in 'Eleanor Rigby' um, even 'Will you still feed me when I'm 64' , um, 'Yesterday'. I think there are great popular songs of that period and I'm not familiar enough with the current ones to know whether there is stuff, and I think things like the protest songs of Dylan, I think all of those songs inspired at least '5 foot 2' and 'Universal Soldier' um, those sorts of songs, um I mean there were quite a lot of them which, I mean I've never forgotten. 'The Prostitute' song, I don't know who wrote it, it was in one of the Folk Club magazines that the chorus was 'Forty nine fathers and only one mum'. Incredible.

And again in 'Faith, Hope and Clarity' there was a Deaconess who was working in Soho then with the line you know, 'Our smoke rings are circles of distress' when she was working with the drug addicts and so on. There are powerful lines in there.

I mean the ability to play Folk guitar. I mean I went up to (N)'s house and did a term's lessons and I can play me three chords a bit beyond, not much beyond! I can use a capo but that opened up really - because I learnt it by ear in the way I didn't learn piano - that opened up... So I can only play the guitar by ear and I can find the chords of somebody singing whereas I find that extremely difficult on the piano, so I acquired a completely different skill. Folk guitar was a great help there as well.

I think also what skills, um, I think you know being close to the hymn tradition opened up the possibilities of meter, rhyme all of that, um and how that plays out. I think by being a cradle Anglican and being brought up hearing metrical verse really was hugely important part of that upbringing.

5. *What of your own life experiences do you bring to your professional life that have helped shaped you into the musician that you have become?*

Yes, to a certain extent I've said some of this about Notting Hill and all of that. Um, I think coming to terms with a very difficult and complex past. Um, well I am really glad that I didn't go along the professional musician route. I am really glad now that it hasn't always been in my life; that I didn't leave Oxford and go straight into the world of professional music making, whether I was leading an orchestra - not that I could be playing the violin - but leading an orchestra or conducting an orchestra, standing on that. I mean I am glad that I waited until the South London primary schools, not Prep schools.

I am glad that I gave up teaching when my children were born and I got into the world of Mother and Baby clubs and Toddler clubs and you know the mixture of classes in those, in London, the working classes and middle class people alongside one another. And although that hasn't helped my professional career, indeed when I applied for professorship it was extremely unhelpful, 'cause I was deemed to have a hole in my CV.

The variety of my life I think is quite important, so it is much more various than some traditional professional musicians who've stayed in one particular way of doing it all. So you know I read music at Oxford then I go and teach in South London primary schools. I become Head of Music in a girls grammar school bordering on (N) prison with a large proportion of Jewish children. I give it all up when I have my own children and get into Mother and Baby clubs and Toddler clubs and singing and so on. And then do a PhD but looking at that area of young children, and then become an academic. Um, and so I think that I have a rich experience of life because it's so various and I've associated with a huge range of people, including different ethnicities and so on. I mean even my parish now, I mean its 75 per cent Black, African and Afro Caribbean and the interface dialogue.

I think what I bring is a variety of experiences really. Which has led me to challenge the classical concepts of excellence as being simply, you know, how correctly you play the dots and whether you make a nice sound. And

has enabled me to see music as much more part of the fabric of life and as a useful tool for human beings to enable them to handle the complex fabrics of life and that if it works then its good and if it doesn't then its bad. And I think that's why I took the title of Professor of Applied Music as opposed to Professor of Music because by that time I was more interested in what music could do for human beings, than what human beings could do for music. And I was brought up in a professional world with the philosophy that's really what human beings can do for music.

6. *What are some examples of compositions that you can think of that for you in particular address painful human experiences such as loss, desolation and isolation?*

I think things like 'Eleanor Rigby', I mean I think it's an incredibly powerful song about loneliness and isolation and pointlessness and so on. I mean it never ceases to move me really as a song. Um, I think again after seeing the Tchaikovsky film of those symphonies and sort of filled with his own personal struggles. I always feel the “Crucifixus” from the B Minor Mass unbelievably powerful piece.

Also the other one that I think is unbelievable powerful is “Et incarnatus est”, The Incarnation'. What else is there, um. I think a piece that I always loved

which was about bereavement I suppose you know the Kathleen Ferrier version of 'What is life for me without thee?' From Orpheus and Eurydice, which is about bereavement really.

I mean Hildegard is incredible. “Act from cruel sadness” which sees the sort of blood of heaven and so on, a wound flowing with blood, of cries aloud to the highest and so on which sort of sees the sort of flaw that is denied by the crucifixion.

And then a song that influenced me a great deal (N) who is a friend of (N) and when we were preparing the book called “Music and Conflict Transformation Harmonies and Dissonances in Global Politics”, he talked about his father who had abused him and how he had to go back to his..., to a family reunion to which he didn't want to go. Well he didn't know how he was going to go because he was going to see his Father again and he thought, you know, “I don't know how I'm going to do this,” but he..., in the end he wrote an incredible song and he went back. And the first thing he did was to sing the song to his Father and this enabled him to, basically, have some sort of relationship with his Father that he had never had before. An incredibly powerful song.

“Fathers and Sons since time began,

Iron clad hearts weighing a ton,

A shake of the hand, a slap on the back,

Old memories from a worn leather strap.

The hardest thing for a Father to do,

Isn't swinging an axe or tying little shoes,

It's opening your heart let your spirit shine through,

By showing your son your love.

My Father and me would never agree,

Fussing and fighting since the day I was three,

A giant of steel, who just couldn't feel,

How to show his son his love.

The Autumn winds blew as the young child grew,

As he cursed at a man that he never knew.

While doing the chores, he cursed him much more,

And never gave his Father his love.

Too many days have come out of the past,

And the days of my childhood are out of my grasp.

Now my Father and I both want to cry,

Thinking back on the time that we were denied.

Fathers and sons since time began,

Iron clad hearts weighing a ton,

Shake of the hand, slap on the back,

Old memories from a worn leather strap."

Yes, we have got a web list from this group, and we had one month on those, and there are an incredible number of songs. My contribution really was the song distances you from the emotions at the same time so you are able to stand back a little and not be consumed by them and I think that is

quite important. It’s a holding form and once they're held in some form they are more manageable than when they're sweeping over you in great waves. So I imagined he and I followed that really well. I talked about my relationship with my Mother. We sat in a paella shop in Madrid where we had the conference and he was very interesting really. He said that one of the things that had helped him in the reconciliation process, as you can hear in the text, is to see his Father as a product of a culture so he wasn't just a person. You know the culture had shaped him in some way that made him to be what he was and that comes through in the song.

So I wrote a song to my Mother

“Flesh of one flesh once joined together

Mother and daughter what do you fear ?

Life in its richness has thrown you together

Mother and daughter you are so near.

What can I say of your living together?

How can I speak from the depth of my heart?

How forges the song, the flows, the eddies,

In such a maelstrom, where can I start?

I would remember the colours of Autumn

Treading the beach mast and crunching the snow,

Presents at Christmas and smelling the lilac,

Sweetness and trifles and water soft low.

Time is erasing the times of the weepings,

Loving turned crazy and tears that won’t cry.

Raging and storming and knots of endurance,

And times in the dark and the breath that won’t sigh.

We were both caught in a chain of misusings,

Trapped to men's talents in houses too small.

Bodies mishandled and murmuring madness,

Can we break free from what held us enthrall?

Now with separate livings times easy,

I find forgiveness in wounds that can heal.

Now we can look in the face of the other,

This, then is your song to say how I feel.

Flesh of one flesh once joined together.

Mother and daughter what do you fear?

Life in its richness has thrown you together,

Mother and daughter you are so near."

And that's been sung - I sing that, - as part of the show called "Juggling, A Question of Identity." And usually many people cry in the audience, as people have found with (N), People bring their own suffering and hang it on that. As I say on the web list there is a whole load of them, more of similar songs from around the world. That ability to contain that. So it not only can be done at a cultural level as we heard in Sydney Carter songs in a sense, but it can be done at a personal level.

7. *Have your compositions/performances ever affected the way that family, friends and colleagues related to you?*

Well I think that's the example of it really, I mean the use of that song in that show in particular. I mean if you take that, if you take composition in the

broadest area, the juggling of the question of identity has caused many women to cry and sing the dilemma of the juggling. I mean earlier on in this interview I referred to the variety of things but the need to juggle all of these identities and one of the women who.., there's a wonderful sequence in it where she's got the baby in her arms and she's trying to get to school as she's a teacher, so she puts on her hat and so on and she leaves the baby behind, and she goes to school and she's looking at her watch and she comes back and she can't find the baby, she's trying to get the baby and next time she packs the baby in a polythene bag, and takes it to school and so on. And everybody laughs because it's meant to be funny. But one of the women came up to me afterwards and said “I just sat there and cried because I saw my own life being played out in front of me and I'd never seen it so clearly before.”

That particular show, where the audience are given words, so there are words associated with each of the character um, and so when you come in, you're given – the crone's says 'Another cup of tea Dear?', the Priest says 'I will bless you', the teacher says 'Listen to me', the mother says ' I will nurture you'.

But one of them, which is the wife, says 'Wash, cook, mend, clean. Wash, cook, mend, clean'.

There's a particularly funny sequence because I have got a sort of witch's broomstick, which I brought from Halloween which I am cleaning and I clean

along the audience all along the front and then of course in the end I get stride it as if I am a witch. 'Cause I get faster and faster until I get on it.

But one of the men who was doing counselling with abused women, said I couldn't say that line because that's what they had all been told and I am afraid you couldn't say the line I was given, 'Wash, cook, mend, clean' you know its just, so many women have been told to do that. So that particular show. And I say to people always “Some of this is my life's journey and some of it is not and I'm not going to tell you which.” has been particularly moving for people as a show.

I wrote another piece, fairly early on, a piano piece called 'Anointing the wound' which people have found quite moving which was based on Hildegard's “Crux sanguine” which is quite a dramatic piano piece. That's also has an effect. It is easier for me to do the pieces with strangers than it is to do it with family and friends, much more difficult, I think, with family and friends. Easier to do it with strangers and so on. And my mother of course when I wrote that was long since dead so there was never a chance that she would hear it in this life although I believe she has heard it.

8. *Have you ever felt the need for particular support yourself when creating/re-creating 'dark' pieces of music? If so what form has this support taken?*

I don't, um, I still think that Wordsworth is probably right that when you're composing, it's emotion recollecting tranquility. You know it's emotion recollecting tranquility, that's what Art is. I mean in the darkest times I'm not sure, I don't know though. I mean the 25 Julian pieces were written in a psychiatric hospital so I guess they were written in the darkest times really, although I suspect that at the point when I wrote them, I was coming out of it really. But I don't think the writing of the piece, you know.... I think I would need support at the points where life was dark but that isn't at the point of actually constructing it. It's not to do with the piece itself, No indeed. You know, creating that song, recalling an awful lot of very very difficult memories, but that was lovely. I can still remember sitting in a restaurant and with my paella in front of me in the sun in Madrid and thinking how lovely it was to be able to create it even though what I wrote about were two different things.

I find it also that if I am away... That I do find that travelling away on planes very useful because in a strange way, I mean I've written some really good things in airports. I mean you're in a sort of strange subliminal space really which, you're not really anywhere and that makes it easier.

9 *Do you find that seeking to interpret life's dark experiences gives you any better understanding of those who experience life shadow side 'in the raw' so to speak?*

If one is a survivor oneself of things. I mean the thing that you have, of course, is lots of techniques, otherwise I wouldn't be sitting in front of you. So, you know, life's given you a lot of techniques, certainly. You know, students are sitting here in great distress, um, then that would involve music sometimes. You know, is there a song really that encapsulated...? You know, they've lost a parent or something. Then don't get overwhelmed by it all the time but spend quarter of an hour a night just singing that song, using that as your time of remembrance is just one example really to enable people to survive in ordinary everyday life when, you know, life is hard.

And I think that's quite a useful thing, a song that you know you can use, which is rather like the old Lorica from the Nuns minster in Winchester. and I've used the (N) one, and they all created what are called lorica, lorics being a breast plate, - and we see it in St Patrick's breast plate you know, not that we should be seeing St Patrick (I'm not sure) - or make our own from the things that surround us. So in St (N) in the new pieces St (N) sings, little (N) has come to the Abbey because her parents have died. She is welcomed by (N) and she is really sad and she's really frightened so when Anna sings...

“Circle yourself with the fluff of the clouds,

Wind yourself round with the lowing of cattle,

Bind braid in your hair with something of daisies,

Circle yourself with love.”

...So in a sense she offers little (N) her lorica. And then when the citizens of Romsey are attacked by the Vikings and they all come and say – (N) she's a grown up (N)- ”We're really frightened”, she says, uses her own. I mean we've got it in the Sound of Music now

“Raindrops on roses and whiskers on kittens....,

When the dog bites, when the bee stings,

When I'm feeling sad,

I simply remember my favourite things.”

So you see there is a song that people can use and obviously, um the 23rd psalm is one which of course people have sung of course or said as a way of surviving. In fact I remember taking confirmation classes and suggesting that all my confirmation candidates learn the 23rd psalm by heart. Jolly useful

thing to have to hand when life is rough, to remember, that's right. So I think if you have a song that you can sing. I think of the Caribbean woman that I sat next to in church for 15 years, and I don't think the marriage was great, and she had a big family. And every concert she sang 'One day at a time sweet Jesus' and that's how she lived her life. I mean she lived her life by singing 'One day at a time sweet Jesus' and that was the song that held her life together.

And I think, those sorts of techniques of using music you can pass on to people who are in distress and say, “Well these are some of the ways that human kind have managed to survive”. You need a sort of personal song really. It can be one you've made up and that when you sing that, you're in your own energy and whatever's happening around you can't affect you. Like a shield.

10. *Has performing such pieces rooted in life's painful experiences ever changed your own sense of priorities? Has it caused you to make any major changes in your life?*

I had, what, you know, two small children, a dying mother at that time, a dead father and a dying mother-in-law. I think probably it was hugely complicated, I mean certainly you know, very ill in the hospital, composing those pieces um, based on Julian of Norwich who I was reading at the time. I still look back on them as the seminal pieces, that suddenly I was. Life

outside was completely confused, I mean there was almost nothing of me left. I had two small children, a dying mother who I had huge problems and relationship with and so on. But suddenly to find 25 pieces, I thought “Well, you know maybe life isn't always going to be like this, you know, there is life beyond all of this lot, and I can compose”.

So that was an extraordinary life changing experience in the context of the psychiatric medicine and caused me to rethink, as of course did using my £250 to go and see (N). To dare to call myself a composer. That was what I needed him to tell me that I, that my pieces entitled me to call myself a composer. I mean in a sense the Julian pieces told me that I was a composer so they were seminal really.

As was, I think, probably when I'd come off all the drugs that they pump into you. And I was going to Australia for a six week lecture tour. And I started by versifying Celtic texts so that they could be sung. And because the Celtic hymns had been translated but not in the metrical form and that's where the hymn writing came from really. And I felt slightly insecure really in Australia, because in a sense I had been quite ill before I went and now I was going to embark on a six week lecture tour so who could tell how that would play out. Although I had, I remember there was, one small phial of Valium if things got too bad. But writing those hymns I think. And in a sense, the hymn writer was born there, in writing those hymns.

Well I think it was. In a funny way, I think I learnt the craft there, um 'cause in general I was just diversifying something else, but the whole of the experience of Australia gave me a chance, again a bit like the psychiatric hospital has, to re-evaluate what was going on in life. I mean I was a long way away from it and I could think carefully. Interestingly my youngest son at the time, because he was about 10 or 11 and very close to me said at the airport “Did you have to go so far away for so long Mum?” to which I said to him, well in truth there was no answer really. I think I did need to go away so far for so long really.

I think the hymns, again, gave a sense of other bits I could do, and I mean in a sense... I went back to give a failing marriage one last try and knew that I would give it one last try and that was the end of it. But it gave me that perspective. Um, certainly there was something of, I don't know, one of the hymns I versified which I sing a lot for healing services,

“Give thou to me oh God,

The healing power of your all,

Give thou to me oh God

A place beside the healer of my soul.

Give thou to me Oh God,

A death with joy and peace.”

Which was very different from the sort of death I had planned for myself when I was ill!

“Give thou to me Oh God,

To know the death of Christ

Give thou to me Oh God.

That I may contemplate Christ's agony.

Give thou to me Oh God,

To warm with love of Christ.

Oh thou great God of heaven

Turn thou my soul to thee,

That I repent aright with upright pure

And strength and straightened heart,

A broken heart contrite,

That shall not bend nor yield.

Of angels thou art God,

Bring me to dwell in peace of angels,

Thou art God.

Preserve me from all evil magic charms."

Well that was very much, "Of angels thou art God, please bathe me in your pool". Well I've sung it so many times.

So although that was a Celtic text I was working on it also encapsulated my experience, um, very much as well. It's an extraordinarily powerful song and, you know, if I'm ever present at a healing service, I often will sing that one while the healing is going on.

11. *When immersed in interpreting, through the medium of music, these dark experiences of life, what affect [if any] has this had on your outlook on the world, such as a religious faith or world view.*

Did you say when I am immersed in them? Right. Well I suppose fundamentally I believe that my theology of redemption is that there is

nothing that is unredeemable, um, and the process of making music out of it is redeeming it.

You know the reason I called my music therapy book, sorry, book on music and healing, (“N”) because of the final story, the Jewish story I tell of a Ruler that has a fine diamond. The diamond is dropped and it's broken and everybody says “Oh it can't be repaired” and then in the far flung reaches of the kingdom he finds somebody who carves the most beautiful rose at the point of the crack and indeed the place of the crack is the place of the greatest beauty. So for me, you know, the music is simply, I mean for me it's redemption and that's what it's about, and as a Christian and as a Christian priest my main tool for redemption is really music.

12. *When exploring the painful experiences of life in music, have you found yourself using any recurrent images or symbols? If so, could you tell me what they are?*

Images and symbols, um, well I suppose one of the things that I've tried to redeem you know, in the Christian story, it's not in the Apostle Creed ,it's in the Nicene Creed, “He descended into Hell”, um, and I think that has been quite an important image. That there is no experience that is outside of God's, I don't know, sort of care or experience really I suppose is the

important thing. I guess the 23rd psalm “Yea though I walk through the shadow of the valley of death, I will fear no evil”. I think that is a lie, actually I do fear a lot of evil but I just don't give in to it. But “thy rod and thy staff certainly “comfort me”, I mean, you know that's fine.

I think the psalms of complaint are very important and I prefer them for complaint rather than lament.' Unto thee Oh God do I cry', you know. I mean the Jews were much better at being angry than we Christians are. They were not afraid to call out and I think some of those images..., “How long Lord, how long?”.

And another lovely one that I love. I remember writing in a letter when coming out of the waves of depression was, the wonderful line, and I think its in one of the psalms “And the pools were filled with water, who going through the valley of the wilderness use it for a well, and the pools are filled with water”**.** I think that is a marvellous image.

I think that is what I have tried really. It doesn't feel like it at the time, it feels dry, it feels empty, nothing in it. But actually, at a certain point, the pools underneath start to fill with water and you realise that out of the wilderness will come the water. And there is the sense, there's a bit of Teresa Avalla's 'Interior Castle' where she says that the garden is watered by underground springs. I think those images of supplies, you know, underground and so on.

But that has been an incredibly important text, you know, going through the valley of the wilderness, use it for a well. And the pools are filled with water.

The other thing, and that's a song I wrote again, one of my most, the ones people love the most.' I will hold you in the hollow of my hand'. And that's a song,

“I will hold you in the hollow of my hand, my hand, my hand.

I will hold you in the hollow of my hand.

I will hold you in the hollow of my hand, my hand, my hand,

I will hold you in the hollow of my hand.”

And ' I will hold you with the ripples of the sea, with the blowing of the air. I will hold you with the laughter with your friends', and so on. But that notion of a hand, and the Julian image of “You show me small things the size of a hazelnut”. But that notion of being held.

13. *What role do you think that the arts in general, and music in particular, have in exploring every kind of human encounter? Can uncovering the darker side of human life, be seen in a positive negative or neutral light?*

I think you can do it in a variety of ways. I don't think it necessarily is a good thing. But I think, you know I don't agree with Paul, by his 'Faith, Hope and Love, the greatest of these is love'. I think probably the greatest of these is hope. I think however you portray it, there must always be hope.

One of the images that I remember and very well and one of the betrayals, um.... We had a young playwright here and he wrote a thing about Nuclear War, a terrifying drama where the group of people have the only really fertile bit of earth in the a world that has been destroyed. And they realise that they can't support everybody, in a sense it's a model of the Holocaust in a strange way. But, so when they get rid of people they say they are just going to send them to a better place, you know, to a more beautiful place, but of course they're not. And these people are out there in this nuclear waste and actually at one point they eat one another. So one of them dies and they boil up his bones and eat him and so on and so forth. And the last image, which I think of still, I went through the car-park crying, was a pregnant woman who was bound into a chair and that was the last image, a pregnant woman bound. There's not much more of a powerful symbol of the destruction of the world than a pregnant woman bound. The one bit of new life. And I can remember going away so angry because this was a play which touched on, you know, humankind's greatest fears, you know this was the 1960s.

But also the stuff that is being explored in the PD James, her latest one, but there wasn't an ounce of hope there. In the very darkest place but there was no hope And I think of that portrayal. And I think there is quite a lot of stuff that I think when music got into its really really vicious kind with really really vicious sounds and so on and so forth, it did hold a mirror to society, but not with any hope in it. It is a sort of nihilism. But when we've got these incredibly sort of, you know, discordant pieces with no hope in it at all.... I think drama does it more and I think some of the modern Arts stuff where things are really vicious. But to my mind there always has to be hope. There always has to be hope.

I was trying to think of the PD James book, it's a film that John Tavener wrote part of the music of. But, you know, there's this world of, it's all Gang warfare even in the countryside and so on. I think its something, I can't remember, it was out about two or three years ago, it was a book originally.

And there are three women in it. One of them has got Altzheimer's, the other one is a midwife and another one is a woman who is pregnant. There hasn't been a child born for 25 years and one of those who is now 17 or 25 has just been killed in a pub brawl. And they find the asylum seekers, and the country's against asylum seekers, so they are kept in cages on the streets,. And the story is how to get her through all of this Gang warfare so that she can bear the only child. And the thing is about trying to get her on a ship

called 'Hope' and eventually she does. They do get her through all this. I wish I could remember the name of it but it's PD James. It's not a 'who done it?' but it's more a sense of a millennium view, but in a sense not like the nuclear world of the young playwright. There is hope there and in the end, you know, this little boat that she's in arrives next to this great ship with Hope on it.

So I think it's not necessarily a good thing, and I think... 'cause so much artistic interpretation is between where the artist is and where what is being offered to the audience is that sometimes things are not good for you which might be good for you at other times. You can be in the wrong space for them and so on.

I think that as a creator you need to have hope in your heart and you need to know that it's not just as you say a nihilistic portrayal of horror. Although to a certain extent that holds up a mirror to society but I think you have always to think.... I mean, when I interviewed John Tavener about his music, and we talked about suffering. He said the suffering always had to be transubstantiated, which I thought was an interesting word, and so it must always be. And of course his music does that. He doesn't use any of those more difficult sounds himself, and of course many people find that helpful. But I think there must be hope.

14. *Can there be any mileage to be gained by the arts, including music, taking a contrary position so that rather than uncovering that which is destructive, seeks to uplift the human spirit by focusing on the divine, however that be understood ?*

Well I suppose that is what I mean by hope really. Well that of course is John Tavener's view, you know it must be transubstantiated in some way, um.

Some people call that denial of course. I'm not sure at the end of the day, I don't know. I mean is that song I wrote about my mother beautiful? I think there is a sort of compromise where acknowledging something.... I mean, I think there is some kind of naivete that I find in contemporary Pop but that may be because I am too old. You know there is a naivety often in stuff about loving and so on and so forth, as there is a cruelty about Rap traditions, you know EMINEM and Misogyny and all of that.

So I think neither a concentrating exclusively on the anger nor a concentrating exclusively on the good stuff, I mean, you know, stuff like the Euro-vision Song Contest, “Congratulations and celebrations” those sorts of songs. There's a place for them but there's a naivety about them, um. But I think it's very difficult to write, and to use John Tavener's phrase, transubstantiated music. It's actually much easier to portray the darker bits than it is to portray, certainly in terms of discord and so on, than to write joyful music as opposed to happy music. It is much more difficult to do that,

much, much, much more difficult and you know there is often a naivety about trying to write happy music.

If you think of the church music we often call it 'Happy Clappy' music, there's a naivete about it and so on and so forth. I mean it's always been there, I mean “Yes Jesus loves you, the Bible tells you so” but, um, and some of the more certain... I suppose I find some of the more certain Evangelical hymns in that category, you know. That somehow Christianity has to keep the Crucifixion and the Resurrection together, is just really, really hard but I think the greatest music comes from it.

I don't believe there's that much difference between great pain and great joy because I believe often one does experience some of the deepest joys in some of the hardest bits. In a sense Julian has it where she screams at the crucifix and then says “ But suddenly my sadness turned to joy and I was full merry” you know, and then when I do the one woman show on Julian I say “Well that is the ultimate mystery the joy and the pain” so it's strictly bound together.

So I think the deepest experiences of joy are at the moment when the pain becomes, and again I use John Tavener's phrase, transubstantiated in some way. And that is probably the deepest joy, the joy of survival and so on and

so forth. Um, but I think it's a very hard line to tread, you know to write happy, to write joyful music is the most difficult of all.

I think in the “Quartet for the end of time” Messiaen does get close to it. Tavener did it in the piece that was performed quite recently in the cathedral, um, - I can't remember what it was called now “Out of the silence', something like that, - but it was string quartets and so on around the cathedral, um. And of course I think that Tavener with his slow chords and the “Quartet for the end of the time” as well, They're quite a useful device for that. But I mean, in a sense one is approaching the source of ultimate ministry which is in a sense the life of Jesus where you know the joy and pain are inextricably bound together really and the two are caught up together. You know, the difficulty of the incarnation and so on and so forth. And it's a package but to try and encapsulate that as a composer is, you know, the hardest thing and I'm not sure that we do it very often really or do it very well, one can aspire to it I suppose.

Thank you very much for agreeing to be interviewed.

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I would like to begin by asking you about your development as a professional musician:

1. Could you say something about your professional life as a musician. When did you first become aware that music was to play a pivotal role in your life?

Ok, in that order. Well it's probably easier to do them in reverse to be perfectly honest with you, uh, I have been a practising musician basically since I could speak. My, I'll go into more detail later, but my family were extremely musical and I was brought up in a church environment, my father was a priest so I was very much thrown into the, well couldn't wait to get into the church choir shall I say, um and just loved it, absolutely adored it. Then took up piano and trumpet and various other instruments along the way. Anything I could get my hands on.

And then once I sort of got into my teens I started to write, predominantly popular songs, sort of 'Pop-y' stuff to start off with and then moving down more towards folk.

Then when I came down here [to university] writing more experimental composition. Now my life very much revolves around music, um I run three of

the choirs here in various different repertoires. I also have a pretty successful local band, soul funk band. I still write, as and when I can, which is not very often. I still write and just perform whenever I can really. So yeah.

2. What are some of the key world events that have had a deep effect upon you as a person and therefore as a musician?

Well I think, um, sort of, quite a lot of them have been indirect so I think maybe observation of world events that haven't necessarily affected my life but that have touched me, um very much.

Some of the performances that I did as a student, um, certainly the research that, um went into some of the live art pieces that we did was around Holocaust and that was really quite an interesting experiment because its just that horrible 'sicky' feeling whenever you think, whenever you see any images, um, especially sort of, Auschwitz and things like that just absolutely chills me to the core and if I ever needed to think of something that was frightening that would probably be it.

So, um sort of anything to do with sort of death from unnatural causes, you know, sort of murder and genocide and war is just abhorrent and really does conjure up quite a lot of fear and angst in me. I think anybody, of my generation, our grandparents certainly were there, you know, and have quite a lot to say about it. My grandmother was in the army during the war but as a

musician, which was very interesting, so, yeah and she sort of, sang for the troops essentially and was very, very good at it and led choirs which is now what I'm doing, not in the army and not during the war thank the Lord, but still.

3. Who have been the key musical figures that have shaped your own musical development?

My Father, (N), um he was a Reverend an Anglican priest, an Anglican NSM. Unbelievably talented. Literally the sort of person that could turn his hand to anything, certainly if you could blow it, it would make a nice sound. Oh he was absolutely incredible, um, and er, any sort of key board instrument, guitars, anything at all. So I think he really was a massively key figure in, certainly during my upbringing, in sort of making me aware of the amount of music that I think was accessible for me.

Obviously I grew up in church so a lot of sacred music was very close to me, um, but also he was very much into Irish music. Not Irish himself, funnily enough, but very much into Irish music and a World music as well, so some quite unusual things. And Opera and classical music, lots of Baroque music. So I was exposed to an enormous amount of genres throughout my childhood. And that's definitely something that has continued and has further enhanced my eclectic tastes if you like. And I think, you know with my father, which is obviously what is going to come out now is that my father died when I was 14. Um, and, but with that I almost became even more determined to

continue with my music. Lost my Faith unfortunately at that point, um or realised that maybe it hadn't been there, I don't know, but that's another conversation. But it was a massive blow but I continued to write quite a lot and sort of wrote songs for him and would listen to things to see if I could hear him in them. So my Dad definitely was a huge, huge influence,

With regards to sort of individual artists that I enjoy listening to there's no one person in particular. It's just everyone. And I find that the most inspiring thing for me is actually to work with other people, so, almost regardless of the type of music I'm trying to create. If I am with somebody else, whether they are helping me with the music or not, if they are just in the room and sort of I'm bouncing ideas off them, whether they are a 'musical' in inverted commas person, um, I find that actually that's where my sort of inspiration and of encouragement I think as well, comes from, certainly if I'm writing and I think when I'm performing I thrive off of just the energy that's in the room. And again that's very much determined on who's there. Very much so playing to a crap audience can be enormously difficult. You know, but so can playing to an over-zealous audience as well, is just as troublesome in very different ways,

4. What have been those elements of your musical training that have proved of most use in the exercise of your professional musical life today? As well as being technically competent, what informs your ability to successfully

interpret emotionally charged music, particularly that seeking to convey life's dark side?

Ok, If we're talking about technical proficiency it will be a relatively short document. Um, I obviously, as I said, was brought up in church so I learnt to read music from about the age of 6 or 7, which interestingly enough was just after I had been convinced that I ought to learn how to read words. So that I was then allowed to join the choir.

Yes, it was a bribe " You can join the choir if you learn how to read a book (N)" .And I did, very shortly. So I was literate, musically literate from about the age of 6 or 7 um, and learnt much of my theory sort of, by reception during my very, very early years. I then got extremely bored with anything theoretical and decided I was going to do it 'My way'. And have kind of stuck to that really ever since and I tend to shy away from giving other people manuscript, um, because I find that to teach by reception is actually a much more enjoyable and lasting experience. I think you remember it far better if you actually have to store it in your brain rather than having it on a sheet of paper. And for performance sake it looks so much nicer as well, especially when I'm teaching a choir.

I think experience has been the most beneficial tool in my pencil case really, um, the death of my father was massively, massively shocking, um and I reached some very dark places after he died and you know, wrote some

quite beautiful but almost cringe-worthy stuff that makes you sort of think, you know, you don't really want to hear that, you know, it's almost too much emotion. Because I sort of wanted to express these things but didn't really know how to do it, sort of did it through song but it was just, you know, now I look back at it and think 'Ooh, crikey, that must have been so difficult to listen to'.

I am quite a, I can be quite a dark person. I do have, not necessarily a dark side that comes out in me to other people but I can conjure, sort of very dark emotions and sort of pictures in my head if I need to and I find, certainly as I've got older, sort of, certainly literature and film that is dark fascinates me. I am quite fascinated by the 'dark side', again in inverted commas, of people. But actually by nature I am extremely, sort of, you know, I'm quite extrovert and I'm actually a very happy person but maybe that's some sort of counter balance. But I think just by my nature, um, I like to utilise whatever I can of myself in my work, um, be that in performance, be that in writing, be that just in, you know, administration. I think you need to be able to sort of take hold of every emotion in your kit to be able to deliver something. Certainly if it's, if it's specific, if it's got a specific criteria to fit to. I find that, actually often, if I'm happy I can't write anything at all. I have no creative, not an ounce of creativity in me but actually it's at the dark times in my life that I find it starts to flow. Sort of poetry which then leads to song. I often write words first, in fact I always write the words first, so.

5. What of your own life experiences do you bring to your professional life that have helped shaped you into the musician that you have become?

Numerous, so, deaths of family members and friends are definitely something that's always there, um but also my experience of being a student and the sort the of pros and cons of that. I was enormously homesick when I first came to University. I was sort of 21, I was a few years older than the others but I was just so, so sad and missed my Mum. Missed home. Loved it here but couldn't just quite cut the apron strings, as it were. It's quite difficult. It's a really difficult thing to wrestle with, so, yeah I think death and watching death I think was probably the most terrifying, not even really terrifying, that's the wrong word, I wasn't frightened just so sad. Just so desperately, desperately sad to watch and I watched both my Dad and my Granddad, my paternal Granddad die within 5 months of each other. So it was really a hard time. And I think that especially at the age of 14, I mean crikey your hormones are going bonkers enough as it is.

So I think definitely those um, and the whole experience of coming to University was very difficult and I also had a lot of issues with anxiety when I was younger and depression, um, which now I feel that I'm on the other side of and I feel that I'm on the other side of all of this and that actually when I think about sort of pre Uni, it's a whole different life.

I think there's been three, there was, sort of, zero to 14 while Dad was still with us and there was that weird sort of, 5 years, 6 years, was it 6? 7, 7 years where I was still hanging around at home but Dad wasn't there and then came here and sort of, then began my life as an adult. So it's been, it's really interesting I do compartmentalise my life in my brain, in my memory.

So some very positive things have influenced me enormously but also some very negative things that make me very grateful for what I've got I think. And I think, but I think that feeds in, directly in my passion for performing. I think that's, they are inextricably linked.

I would now like to focus on the theme of the painful experiences of life explored in music.

6. What are some examples of compositions that you can think of that for you in particular address painful human experiences such as loss, desolation and isolation?

Most of my back catalogue! There was the piece that I wrote for my Father, um, after he died, which, cringingly enough, was called 'Dedication' you know that was about 'It's so sad that you've left, I can't believe you've gone, why have you been taken away from me' real sort of angry, angry teen-aged, teenage angst in a, in song. So that was kind of the beginning of it really. It went on from there and I started writing I mean most of my, certainly my teenage songs were really quite sad. Not obviously so but sort of certainly subtext.

I remember when I was doing work experience at a school, near my school when I was in year 10, so that was actually just, just before my Dad died and I wrote my first song and it was called 'Gypsy Girl' and it was about this girl that just made me feel so sad because she was very odd, everybody bullied her, nobody really liked her but she was beautiful, absolutely beautiful and very, very talented actually and I just wrote this song because everybody used to call her a 'Gypo', she was sort of curly hair and a bit scruffy and wore unusual clothes and, but I wrote this song called 'Gypsy Girl' for her and that was, you know, extremely sad at the core but actually the song itself was quite positive but it had come out of, was born out of something that I'd seen was quite sad experience.

Barber' s 'Adagio for Strings' played an enormous part in my life when Dad died, um I just, it was so mournful and I didn't know it very well at that point it wasn't sort of, as overplayed as it is now, but it just, I found it was the one thing that I could absolutely guarantee would make me cry if needed to. And actually that's a very important part of, 'cause sometimes I think when you're grieving you do get to that point where you just cannot cry any more but you need to, you know, not publicly you don't need people to see it, you just need to be able to sob and, you know 'get it all out'.And so I used to just listen to that over and over again, um, for quite some time.

Then, unfortunately, I lost a very dear friend of mine to suicide when I was 18, she was the same age as me, um, she shot herself, and it was just about the time that Coldplay became sort of, globally famous and they wrote a song called 'Trouble' and now I can listen to it in a very similar way to 'Adagio for Strings' actually. I find that it helps me to release if I'm feeling really anxious and need to have a good sob. But at the time it just destroyed me. I just couldn't listen to it and again it was the combination of some really quite deep but ambiguous lyrics, so very, sort of, open to subjective interpretation, um, but also what I thought was a very beautiful chord structure and some very pretty piano and it was just made for that moment really for me and was something that was in my collection at the time.

Then similarly a couple of years ago I was in an abusive relationship. And when that sort of started to become evidently a bad idea, and I didn't quite know what to do, it was another Coldplay song which, I am almost embarrassed to say but I actually quite admire them. I actually quite like some of their material even though it's something I don't generally listen to any more at that time it was, um and it was 'Fix You' their song 'Fix You' which the partner that I was with was an alcoholic, um and, although I never truly believed that I could, I really wanted to be the person that would help him through it. Not for any personal gratification but just because I loved him so much I thought that that would be, I thought that would be, I thought that it was my job, this was my destination in life was actually to just get him away

from it, um and I didn't and then he ended up breaking my nose which wasn't very nice.

But now, again, I have a completely different relationship with that song because I've grown so much since two years ago now that song is actually very powerful and that's a real 'power' song for me, a bit of a, you know, a bit of a 'fingers up at him' really.

Very strange, yeah, time and music have an effect on each other**,** I think, we can escape the time we are experiencing right now by listening to something. If we want some sort of escapism we can listen to something that helps us to reach that place but also we can, we use time to alter our perception that we actually use it but time does alter our perception of music.

You know you hear a song for the first time and it touches you but then many years later you may be completely cold to it or visa versa, and there are songs that definitely grow on you. I always maintained that that wasn't possible but they really do, they really do.

And again I think as a performer there are some things that I do not like to listen to, 'musical theatre' for one. My house mate, (N), is absolutely bonkers about musical theatre, he loves it, he loves listening to it, watching it, being in it, whatever. I am cold to most of it, certainly commercial musical theatre, um

but I love to perform it. I absolutely adore performing it so it's really odd that my performance and my love of listening to music are really quite far removed from each other.

And I love choral music but there's not a lot that out of choice, well there is a lot but as a general rule I don't listen to choral music unless I am actually there and doing it myself, so, yeah.

For me performance is where my passion is, that's totally where my heart is and it's a very difficult thing to express actually in words because it's such a, it's such a physical experience and that sounds very 'Arty Farty' I know but it really is actually communicating. I truly believe that, I truly believe you know, that Ok, I'm agnostic I believe there's something there but not necessarily God and not necessarily, certainly not necessarily Jesus, I have issues with the Bible but I'm not completely cold to it, you know, I understand, and my 'Spirituality' is in music and I think always, always has been and stemming back to sort of before Dad died that was when I realised 'Ah, maybe I was never actually Religious, so to speak, but I have always been very spiritual' and that music is what touches me, and that sacred music really touches me, even though I don't necessarily believe what the composer may have um... Yeah and I think fine and now I've realised that and now I have 'problemised' that with myself and sort of 'beat myself up' for years about not having any faith and sort of been to Alpha courses and all sorts of things like that and going 'No, there just isn't any there' I cannot believe it, there's too much science.

7. Have your compositions/performances ever affected the way that family, friends and colleagues related to you?

Yes, I think because I make friends very, very easily and a lot of my, certainly my choristers, in my Gospel choir and in (N)'s Singers, um they're all based here in foundation music. A lot of those people are my friends, primarily they are my choristers because that's where I've met most of them through but they are my friends as well. When I am leading, that is definitely a performance, it's an absolutely one hundred per cent honest but it's a performance but it's '(N) in choir mistress mode' you know? It's quite a different, I'm quite a different person, um and I think people treat me quite differently once they've been a part of that.

I can't comment for them but they definitely treat me differently, positively, not very often is there anything sort of negative that comes back, but certainly differences in behaviour once people have been part of something like that with me.

I did some quite profound, well I thought it was quite profound at the time, some naked performances while I was a student that were about various different things. The one that I did here was about the subjectivity of beauty and at the time I was about nearly 20 stone and I did a cat walk and used

music and clothes and I sort of identified what I would want to listen to when I was wearing particular outfits and I did sort of, mathematical cat walk that was all about time and um, exactly, very precisely movements and then my last performance was 8 minutes long to sort of represent the eighth day of the week when actually underneath all of the 7 days of the week you're completely naked anyway. And I, and the music that came from that was very organic and was my own and I just stood in the middle of a room completely stark and um, my colleagues were there, my course mates were there and were just absolutely 'gob smacked'. But again the reaction from that was really beautiful, everybody just thought it was beautiful.

I've always been quite frightened of people thinking that I'm a show off but I am actually a bit of a show off and certainly in things like Gospel choir I am like, damn right I'm a show off, I'm actually very flamboyant and I like that and that's what drives it, that's what makes it drive. And that feeds into my life as well but I think when it comes to very private and personal and solo performance it's a completely different kettle of fish and I'm actually quite protective of it. Not in a 'hands off I don't want you to know what it's all about' absolutely not, but I'm quite protective of myself in that I am frightened if people think I'm doing it for therapy or I'm frightened that they think I'm doing it to show off, actually, no, I am using it as a tool to express something that is quite profound within me, whether it's quite profound within them, my audience, is a different matter entirely. Actually it's a tool for expression and

if you don't express things then they just sit there and bubble away under the surface.

8. Have you ever felt the need for particular support yourself when creating/re-creating 'dark' pieces of music? If so what form has this support taken?

I think I've already answered this I can be quite a dark person. I find that, if I'm happy I can't write anything at all. It's actually at the dark times in my life that I find it starts to flow. But if we need to, I think we can escape the time we are experiencing right now by listening to something. If we want some sort of escapism we can listen to something that helps us to reach that place.

I would now like to explore the effect that the painful experiences of life explored in music can have on the way that you live your life day by day.

9 Do you find that seeking to interpret life's dark experiences gives you any better understanding of those who experience life shadow side 'in the raw' so to speak?

Yes, I think it does and I think again music is an extremely communicative tool and whether it's that, I find singing for the elderly to be a completely different experience to singing for, sort of young and middle aged people, um and I think that again brings us back to time and what can get attached to music throughout time in one's own memory and emotional infrastructure, if

you like. And I found that actually, that sort of therapeutic side of music for the older generation is very touching.

Again it's something I'm a little bit frightened off because I do get frightened what I'm going to dig up something that they might not want to dig up, for, you know I'm going to bring back something that actually is far too painful for them to experience, um but I think, certainly with peers using performance to extricate some trapped emotion is really effective. But again only if they want to. Only if people want to experience that and see it for what it is.

I wrote, I've never quite realised quite how much about my performance history has been about these sort of issues but it's all coming out now. My dissertation was about the subjectivity of interpretation in the finish and it was half performance and half written work but it was about, to start off with, I was looking at the performative aspects of the grieving process and I was basically going back through the memories of the death of Dad and of various other people and um, I actually found it to be too much and it started becoming self therapy which I had to sort of turn my back on a little bit, because I thought 'right, ok, this is third year of my degree I'm probably going to be a bit stressed anyway let's not get self depressed as well, or you know regressing to some really quite dark times'.

But I wrote some very beautiful poetry, I say poetry, text, um around the ideas and the piece ended up being called 'Slightly Yellow Dog Collars Under My Bed' because it's one of the things I kept of my Dads. My Dad always used wonderful aftershave and he was also a smoker so he always smelt a little bit of fags and a little bit of aftershave and I kept these, it was brilliant, and I kept these dog collars for about ten years and I would keep them under my bed and it wasn't until I finally went 'right, ok they don't even smell of anything any more, I'd better throw them away'. And his smell was sort of really important just now I think about it, and I think it was just a little bit creepy, but at the time it was just so. It was such a part of him and I think smell can be so evocative, so evocative.

I mean you here of people who have synaesthesia and things like that where they hear in colour. My friend who is a composer she hears in colour and writes her music in the themes of colour, which absolutely fascinates me. But smell almost has that effect on me actually that it really evokes not only memory of events and of music and of people and it's really quite unusual. Anyway this piece, this piece that I wrote I felt, I felt that I couldn't abandon that material that I'd written through what actually was a very short process in the end for that particular subject, because it was just too much for that time of my life and maybe didn't really need to be, um explored in that great a depth, um, certainly not then and maybe not now either, um but I still tailored that performance very much around the idea of, that death is there. That grieving process, that personal side of me, um that I am always very honest

about but I don't really want it to colour how people feel about me. And see me as, you know, 'oh, what a poor thing'. I don't want pity. I don't want that.

I mean sometimes yes, if something really dreadful happens you definitely want it and you want people to come and help pick up the pieces. But actually day to day life, it's now becoming less of an exposed issue for me. But also within that performance I was very much looking at the comic side of my character and that actually I do quite like being a bit of a comedienne.

And that isn't it wonderful to laugh about the stupid little things that you do? You know, having a bit of an obsession with nice crisp envelopes that are hand written that land on your door mat and you just stand there pontificating about who it might be from, you know.

And yeah it was, that was also the balance about the sadness and actually the relative joy that I've had in my life. But also it was all completely jumbled up and twisted because I wanted people to interpret it in exactly the way that they wanted to and the whole point of it was, the whole point of the text was saying that I am so, you know, I want everybody to know exactly what I'm about, I'm honest, my main, the point of my life is honesty, but I've done a performance and a solo project for a year where nobody's been allowed to know what it's about. So I've had to keep secrets from those people for a

year about my honest performance. Which was, there was such a sort of conflict in my process and the performance and then actually me as an individual not just as a performer but just as a human being, that I sort of thrive on, you know honest reactions to things and I had to keep all this a secret from the people that I really very dearly loved, so. All this in my FYP my final year performance. The 'Subjectivity of Interpretation'. I think I called it 'Whose Meaning is it Anyway?'

10. Has performing such pieces rooted in life's painful experiences ever changed your own sense of priorities? Has it caused you to make any major changes in your life?

I think actually, again it's this question of expression and how far you can go with it, um for yourself and for other people I think but for me performing pain regardless of whether it's, um visible to the audience or not, whether it's obvious to the audience or not, is definitely therapeutic and I've certainly never kept it a secret from anybody. But sometimes there are pieces that can be very, very evocative and take you to some very, very dark places. But in going there more than sort of, you know, certainly more than once, what am I trying to say? The more you visit those places so the more you hear that piece of music, you sing that piece of music, you see that film, act that play whatever, um the lighter that dark place becomes.

And certainly for me Bruckner's 'Locus iste'. Oh, it just moves me beyond belief and I actually had it as part of 'Slightly Yellow Dog Collars Under the Bed', I was humming it from the back while the audience were sort of coming into the space and it just moves me so very, very much but it can take me to a number of different places depending on what, how I'm feeling actually and what I'm thinking about and where I hear it. If I hear it in a sacred setting it often makes me very sad, um and makes me cry but also makes me feel very uplifted and very spiritual, um almost at the same time.

I had a bit of an issue with going to churches for a little while after, well no, not immediately after Dad died, but sort of late teens I suddenly found that they were actually a very difficult place for me to be because I really didn't understand what was going on and I had such respect for the spaces themselves but such anger with their, with the religion really. I had a lot of angst with Christianity and some real issues that I had to sort of go through before I could then feel comfortable there again. Because I do honestly believe that they are buildings that should be treated with one hundred percent respect, um. But I think performing your dark side, very openly is probably quite dangerous for yourself and for your audience. OK you could argue what is obvious? Define obvious, what is the criteria for obvious? but actually acting out something that is horrendous for you, sorry, horrendous for me, I don't think I could actually act it out. I think the less that people can, the less that people can relate to whatever experience it is that you are performing, the less tangible it seems for them and think then probably the less comfortable they feel with the material that you are dealing with. So if I was quite literally to sit and read a transcript of the day that my Dad died, I

mean it would be awful, how could that be anything but sad for everybody? And I don't really want to make other people sad. That doesn't, that doesn't do anything for me, that just makes me feel like, 'well I've shared my pain but now I've made you feel even worse'.

I guess you could argue the case for this I suppose if you thought that people needed to be challenged, that they had become immune when this would be almost the opposite of therapy actually, yeah. And I think that if you can leave things slightly ambiguous and open to interpretation. Again I am sort of, I looked at, I applied the theories of Stanley Fish and Roland Bart to my dissertation. I looked at 'Death of the Author' and 'Interpretive Communities' which was really interesting and well I'll give you a copy of my dissertation if you want to have a read.

That whole sort of idea of the death of the author I think immediately I could relate to it because it is so linked to how I deliver my material and that as soon as it has left me it really is in your hands to interpret as you wish really. 'Death of an Author', it's really fascinating it’s, I mean it’s in the real simple critical theory books. It’s probably the most concise way to understand it rather than getting into it because it’s quite difficult when you get to the nuts and bolts. So it's, who kind of owns? It's ownership of meaning. It's very much ownership of meaning and um whether there needs to be any sort of meaning hierarchy. My belief really is that you shouldn't have to ask the

performer what it is about 'cause it's not really theirs, if they've shared it. If I've shared something with you then it’s no longer just mine, it actually becomes yours to interpret how you wish. It's information and it's interpretation so it's that sort of idea.

11. When immersed in interpreting, through the medium of music, these dark experiences of life, what effect [if any] has this had on your outlook on the world, such as a religious faith or world view.

Yeah really quite profound impact on my views on religion, um I have struggled with the concepts of religion for a very, very long time and through. But through music I've been able to keep a connection with the aspects of religion that I do enjoy which are music, choral music, gospel music and various other types of religious, religiously inspired music.

And the community, the sort of the church community and with theology as well. I think that I am almost more interested in the concepts of various different theologians now that I've actually come to terms with where I sit with God and certainly where I sit with Christianity. I am even more fascinated by theology. It's not something that I would necessarily want to be, you know, book smart on really but I find theological discussion absolutely fascinating, I really do and a lot of that I think stems back to, you know, because my Dad was a priest but also a fantastic scientist and mathematician, a musician. So you kind of think, I still am just in awe of, and disbelief, you know, How? How

could he have all things conflicting knowledges? I mean, but still manage to sort of balance being a minister.

What is true faith? And (N) likewise, she is, she's just a fascinating woman who has been an enormous inspiration, um through, you know I mean through discussion that we've had about sort of painful experiences and things like that and she's been there for me throughout the whole, um last, well, what is it now ? nearly 6 years we've been and certainly for 3 or 4 years we've been working side by side and now we really do work as everyday colleagues and I find her concepts of theology really, absolutely fascinating, and how she can balance that spirituality with her wisdom actually and her sort of received knowledge I guess, through her studies.

And through her music. I mean she's a genius and just seems to bash out tune after tune after tune and the words more than anything. I mean she finds such beautiful spiritual text that I know comes from her directly. It's sort of incredible spiritual vocabulary that I think as I spend more time with her I've started to tap into as well. She's been an enormous influence on my life actually and she's the reason I'm still in (N) really. So, yeah, I owe an awful lot to (N) and she helped me with a lot of personal issues I had about my Dad and about my ex-partner as well. That was, she was really there for me with that.

And through music again, we kind of, we manage to get by without saying anything. Several times just by there being the presence of music that we knew meant something to one another even if it was slightly different, slightly different interpretation, she knew that it was, that I was OK so**,** yeah, she's been fabulous.

12. When exploring the painful experiences of life in music, have you found yourself using any recurrent images or symbols? If so, could you tell me what they are?

For a long time, I wouldn't necessarily call it a recurrent image or symbol but for a very long time I've found it nigh on impossible to write anything that wasn't in a minor key. And I mean for several years I was, I could not get away from writing 'sad' in inverted commas, music. Mm, yeah and actually that I wanted to, even sort of, my creative bone wanted to write sort of moving mournful stuff, um but I think that is probably the only recurring theme as such other than I am completely addicted to harmony. I am just a harmony junkie and that's where again, that's where my kind of my upbringing of singing in choir and understanding what harmony was all about and feeling harmony was all about more than anything, um that's, that's really where that stems from and now I find that whenever I'm singing along to the radio even, a simple a task as that is I will have to add a third harmony in somewhere or other, you know a nice little clashes here there and

everywhere. So yeah, I think, I think harmony is always present and then, yeah, actually quite a lot of the time wanting to write sad tunes. Mm, yeah I find it difficult to get away.

13. What role do you think that the arts in general, and music in particular, have in exploring every kind of human encounter? Can uncovering the darker side of human life, be seen in a positive negative or neutral light?

Well I think, I think all Art forms are discursive of, sort of human life as such so it is quite an ambiguous question really. I think, I think music does it particularly well, um in that you are marrying most of the time some, you're marrying words with some quite well thought through, for want of a better explanation, for my music anyway, chord progressions, you know, the rising and the falling of where the music is actually headed, um and that in itself is enormously expressive and I think again because of that subjectivity of interpretation I think regardless of who is listening to it there will be something in there, whether they like it or not, whether they enjoy it or not is a completely different matter, but I think most people can connect to music in general, um and most people find that part of their, I say most people that is a massive statement I know but certainly most people that I know use music as a tool for expression, either for them to perform and use it to express something, whether it's a borrowed expression of somebody else's work or whether it's organic and it's their own, um but also for people who aren't

artistic that wish they could express they find that listening to somebody else's expression can actually be enormously rewarding. So that kind of answers that, the first part of that question. And can you read the second part again please?

Again I think it's so subjective to the situation isn't it? To the individual involved. Again this sort of brings me back to sort of thinking about the elderly. There's some things that, like my grandparents for example, they are absolutely incredible people, on my Mum's side, my Mum's Mum and Dad and my Grandma is now blind and my Grandfather had a stroke, um, golly about 18 months, two years ago now and they're now in a beautiful home and, you know other than the stroke and the blindness they are actually relatively well and I'm enormously lucky that they are still with us. But there are certain things that I wouldn't want to speak with them abou, because I just know that there are some places that it would just be too much. I mean that's my perception. That's my interpretation, that's, that's me probably being a little bit over cautious maybe, but I think there are places that I just wouldn't want to send them too because it would make them too sad.

And there are, and especially with my Granddad funnily enough. I think, you know I've seen a sort of pattern in people I know as they've got older that they've actually become much more emotionally expressive. You know my Granddad is far more likely to cry than my Grandma is, and actually I find

that very beautiful but also very upsetting, you know, watching somebody that has been such a figure of authority cry is really quite a difficult thing to struggle with.

I think, but then again, I think, like we were discussing earlier, you know somebody has lost contact really with themselves then no, you get in there and uncover it, through what ever means you can, I have, you know close friends who are struggling with some really dark, dark horrible experiences that they've had in their lives, and they've been there for a long time and it's taken them a very, very long time for them to be able to do anything about them, be it through counselling or through any other form of therapy. But I think once you are on the, once you're kind of on the roller coaster you have to just keep going until you get to the end. And then no matter what the answer is at the end at least you've got one.

So, and I think again that music does that very, very well. You know somebody's just sad and depressed and doesn't know what to do with themself, and just catatonic almost, you know, when you're so sad that you can't cry, like I said earlier. Then music can really speak to that sort of, almost absent, absent sadness or absent physical sadness, um because as sad as we can be inside, we can look, ostensibly we can be fine. That sort of terribly, terribly British 'stiff upper lip'. But I think, so I think, kind of actually it can be all three. I think it can be positive, I think it can be negative, um and, I

don't know maybe it can't necessarily be neutral. I think it's really subjective, that's my opinion.

14. Can there be any mileage to be gained by the arts, including music, taking a contrary position so that rather than uncovering that which is destructive, seeks to uplift the human spirit by focusing on the divine, however that be understood ?

Yea, I don't think it**,** I mean it doesn't all need to be doom and gloom to make you feel better about yourself. I mean that's actually quite a contradictory.. Again that's enormously subjective. I think for some people they might just think 'oh you're just trying to divert me away from the sadness', um and I do believe that it is good to be sad sometimes and that's again completely according to the individual. One needs to be left alone and left to be sad. Not left alone but actually they need to go through that, they don't need to be cheered up, they need to get through whatever the pain is and really feel it to then improve and have, and improve their quality of life.

I think some people quite like being sad people, um and don't necessarily want to be happy, if that makes any sense. They are, they're absolutely one hundred per cent certain that this is the way they are going to be and there's no changing it. Whether that is the truth or not is a completely different matter but, um I think it always has to be somebody's decision as to whether they want to try to tap into any therapy. You know whether that's with

encouragement is another matter. I think we thrive off encouragement, I certainly do.

There's um, I think there's a lot to be said for escapism and I think when people are very sad and they don't want to be, through experiencing something 'Divine' or just, put it a little bit simpler, something positive. Something very positive and pro-active as well. Something that has a real purpose, that isn't necessarily just to make you feel better. So you are actually doing something maybe for somebody else, maybe it's making something material, whether its for, you know for financial gain, you know, whether that's for fund raising or for personal financial gain.

You know I think actually having, I think when people get very, very sad they get so trapped within themselves and within this kind of horrible little blob of emotion that it is actually really difficult to get out of it unless there's a real purpose for doing so. So I think that, again, the Arts, is a fantastic way to do be able to do that.

Again we look at the fund raising idea, look at the sort of Charities. I mean you have Charity concerts, you have Charity performances of sort of musicals, um Charity fêtes and things like that. You can look at the Arts as being, you know, cake decorating for example, something like that.

You know, not necessarily the 'Arts' in inverted commas, but creative, um creative activities and that really could be any number of things.

I've just started my Masters in Culture and Arts Management. We're looking at what it is to be a manager and what it's like to be a manager in a creative industry. Therefore define creative industry. You know, yeah, but actually you look, you look at most things and there's something creative in there. You know, you look at, I think one of the examples I've, I've, I can't remember which book it was from but like the intricate components of cars for example, and actually how beautiful they are and how incredibly well-crafted they are. That wonderful car advert, was it Honda? I think it was Honda advert, amazing. And there is the car part orchestra is still functioning. You know it's kind of, it's beautiful but I think in anything that's, anything that is accessible and purposeful can be, can be viewed as therapy really I think, and can be a way out, a way out of that bubble.

Thank you very much for agreeing to be interviewed.

Transcription 103

I would like to begin by asking you about your development as a professional musician:

1. Could you say something about your professional life as a musician. When did you first become aware that music was to play a pivotal role in your life?

That's quite an easy answer in that like I think a lot of musicians and artists, it became eventually the only thing I really felt I could do and wanted to do. I had a singing teacher at one point who believed, I think in some ways rightly, that you pursued something if that simply was the only thing you were going to do, and he in some ways dissuaded people, not me because it was a lot later that I started studying singing um, and it came about because in those sort of far flung years, sort of 45 years ago, one had thought of learning the piano and you had sort of strangely enough I started to learn the piano um, with the then our local vicar's wife who then went on to be (N) Bishop of (N) and his wife (N) died just last week. But I started with her and she rather gave me up as a bad job, I think I wasn't practising and eventually I went to my Secondary school and our form teacher happened to be our second music teacher.

He missed a parent's evening because I think he had the flu or something and obviously he couldn't, it was a huge school, and he couldn't go round and see all the students he taught, but he was prepared to go round and see those in his form. He came round and saw my parents because it happened to be on the way. He lived in (N) my parents lived in (N) my mother still does, and he dropped in, had a cup of tea talked about what I was like in school and as he left, my mother said “Well as you're the music teacher you don't know anyone or would you be able to take Jonathan on?” and he took me on as a trumpeter and a pianist um and somehow we clicked I think.

I don't specifically remember clicking but within about 2, 3 years I got a Junior Exhibition to Trinity College of Music and that really was all I was then going to do. In some respects I think I became a bit too channelled really. I remember at school thinking why do I have to do Maths, actually sort of having discussions with the staff, I don't need it, very foolish because now of course when I do my accounts I think I wish I understood it more despite the fact that you've got, you know, calculators and computers.

But that was it really, and then everything grew from that. The reason I became a conductor was again by chance, it wasn't any sense of me thinking I'm special or particularly talented. This music teacher left after a year, he still taught me privately which I now realise was a tremendous stroke of luck, I mean had he not been driving that way home, he would have probably have turned round and said “Mrs (N) your son better find someone else.” But he left the school and he had already started a sort of brass ensemble which I

then took on. And then by taking that ensemble on and enlarging it to a little, well not so little actually, a fair sized youth band, um,

I then conducted another band in my own home town and we needed to raise money to put the band in what in those days was called low pitch, it was in old fashioned high pitch, bands were in a high pitch and if you were in a high pitch it was a nightmare for other people joining and we had to have little bands put round all the slides. I think it probably cost as much as about £200 but one Christmas we went 'carol playing' round local towns and villages, made some money for it and then I think in the summer, well I know in the summer to continue to raise money, in my parent's garden we put on a performance of Mozart's very early little opera he wrote when he was 12 or something, 'Bastien and Bastienne', so I then moved into conducting orchestras and then of course came the Royal College of Music.

So in short it was all chance. It was all chance. I really can honestly really say I don't, I think my Mother now if she were here to be interviewed she probably wouldn't say “Oh yes he simply went on at us and on at us until we found lessons for him.” Because I wanted to play the clarinet which my brother learnt, and the nearest clarinet teacher was(N), all of twenty minutes drive but I mean that was impossible, no-one was going to drive to (N) so I ended up learning, started on the cornet which my Father played because he was in the Royal Marines, my Father was in the Royal Marines and I am

always quite interested by the fact that it was chance and now I wouldn't do anything else. I mean occasionally I get in a depression about the frustrations of the musical world I am in and think 'ah, I would like to go into antiques, think I'd like to go into counselling or I think I'd like to go into, um food, you know, cooking, learn to be a chef.' but then I think well actually I can't live without this, I can't... It's sort of essential. It's amazing. And the making of music, particularly in the world I am in which is dealing with a lot of amateurs. I mean I often say when I'm in the orchestra I will come along and do a rehearsal, I mean a night like tonight, blowy evening, and you think 'Gosh, do I really want to drive all that way down'. And then I leave and it is so rewarding and you think everyone has given so much and we've achieved something in a nice atmosphere. It doesn't happen everywhere. Very good people.

2. What are some of the key world events that have had a deep effect upon you as a person and therefore as a musician?

Key world events, Golly, that's hard. I mean if you ask me the sort of, the single most, memorable is the wrong word, shall we say the single one that one would always remember is the Twin Towers coming down and very bizarrely enough I knew nothing about it happening as nobody, as anybody is in the same boat but I was coming down to the Island and I arrived at the (N) and uh, I think (N) most have picked me up but he I think he didn't know anything about it, came in and his wife, (N), just said " Come and look" and there it was.

But how did it affect me as a musician? I am quite cold about these things. I think,... I know it's going slightly away from your question but I think I'm more affected by somebody that I've known within that set up whether it be a choir or one of my orchestras. You know, I mean, Nelson Mandela being released was important but I often feel these things are too far away from me for me to do anything except grasp that it is terrible and how can this sort of thing happen and continue to happen because in various levels, you know, they happen everyday.

But emotionally if I've had, I mean in (N) Philharmonic, we had a marvellous chap, really, chairman of the orchestra and treasurer for years and years and years and suddenly, you know, we knew he was dying. And it was a terrible shock for us all and he sat in the second trumpet position for ever and they always say don't they 'when one door closes another opens' and when we didn't know he was ill a new quite young girl had came in to play trumpet and he would say jokingly, he would say to me things like " Well of course you won't want me now." and I would say "(N) this orchestra wouldn't exist without you. Of course we want you." And he was a wag, he was very amusing and he had this lovely way of talking to the orchestra, in a rather derogatory way, and I'd say "Oh don't be ridiculous (N) isn't going to push you out of the position." and then of course he died and there she was, she stepped in but I never forget saying, because, perhaps the next concert afterwards we dedicated to him and I think we all felt very, very emotionally

drained by it and I just said to (N) at the end of the concert “ Could you just leave your seat, leave the second trumpet seat and just quietly go into the wings, don't say it.” and the concert ended and we all stood and whatever and I came back and I just pointed to the empty second trumpet seat and that was almost too theatrical but I just turned because everybody knew it was too (N) and we were all very, very choked by. But you know, it's somebody you know.

It's, yeah, I think that's me really. I don't, I mean, you know I'm not, I suppose if I'm there but, you know Armistice Day and you see these old soldiers, and you know those who remember them and it is terribly moving but even on the television I'm not that moved by it but you go there. I think when I played the 'Last Post' when I was in my teens and my twenties that was pretty lip trembling when you're absolutely there and 'They shall not grow old as we that are left.” ...It kind of falls on you doesn't it? There's a whole moment when everything falls on that particular person...Oh ,it's dreadful, dreadful. I don't think I'd ever do it now. The old soldiers are really looking to you to emote musically so that they can release, remembering all those many, many years ago that they lost very,very close friends. I suppose that is what you are trying to do for most concerts really, give people an emotional experience, as I said coming along here, whether it be transported to paradise or just something extremely interesting.

3. Who have been the key musical figures that have shaped your own musical development?

Very easy. First of all there's this teacher who I mean I wrote to him simply the other day simply because we have a reunion and I, he wasn't sure because he was only at the school for a short time and I'm still not sure if he's going to come and I said “You really do need to know, and this is not me buttering up, Without you I would not be doing this chosen career.” And wouldn't, it just wouldn't have happened and I think again it was all to do with the fact, and again I never thought about this until recently and really this specific point talking to you, the fact that he was driving this way, he would come in and I never forgot my Mother would always bring him a cup of tea and a nice piece of home-made cake and, you know, I think this were all the things. And we lived in a beautiful Mill house and it was probably a lovely experience for him to come in and I was probably a complete brat but I did something and I got going, so him.

And also, again we were talking a little bit about Primary school. We had a music teacher who could really play the piano. I mean she was a proper pianist, she played for local choirs and things as opposed to quite a lot you discover nowadays who have to rely on music tapes, you know music tapes to go along with. And let's face it that's, you're not physically involved as you, you know in your teaching you’re sitting there and you’re singing with the children, you're enjoying.

They're getting something extra because they're seeing Sir or Miss play.

And then at the, I mean lots of interim teachers in Junior College but at the Royal College of Music the main influences were (N) my tutor ,who one sort of, is sort of encyclopaedic in the back of your head, not just about what he knew because, I mean he knew far more than I'll ever know in my entire life about music and he was very,very scholarly but the way he worked. One of the things he continually said to us “Don't just rehearse things without explaining to be people why you are rehearsing.” Because otherwise they just go “Why is (N) doing that again?, Wasn't it all right?” Or “Why aren't ?”

And then (N) who I found an inspiration. And I found him to be a very, dare I say, a friend because he helped me out quite a lot. I mean when one was a bit green about ordering music. I was doing a Christmas concert where I needed the brass ensemble parts for the Rutter 'Twelve Days of Christmas' and in those days I think, it maybe even now, OUP were sticklers. If you didn't get your music ordered, because they had so many orders, by the 1st December. 2nd, 3rd December you rang up “Could you?”, “No, no” it was too late, “Sorry, we've got so many orders out you've had it.” And I was rather embarrassed with this vast choir in (N) I was conducting. I thought, crikey if I muck this up, but I just rang (N) up and said “Do you have your own set of parts of the 'Twelve Days'?” “I do.” “Are you using them this Christmas?” “No

I am not.” “Could I borrow them?” “Yes you can.” And, you know, that's slightly 'Old boy's network'.

And then to answer this, so I don't get sort of waylaid for (N). When I was at (N). which was really exciting and I got to know him probably better than anyone else there. So much so that the Mill house I mentioned earlier, we were in the garden, as a sort of family one Saturday? One Sunday? I don't know and there were paths, it was a rather large garden of paths and herbaceous borders and we had a garden room. It all sounds a bit idyllic, it was quite idyllic.

We had a garden room of which to get to the particular lawn we were on you had to go round, but my Mother was obviously in the house or something, she heard the phone ring and answered in the garden room and just walked straight through the herbaceous border and said “(N) is on the phone.” and he, well I answered the phone because a little known fact is that (N) is an anagram of Schubert without the 'S'. Complete nonsense but he knew that. I never knew that. So he called me Schubert, and he just said “Is that Schubert?” I mean I had seen him in the summer and he just said “I'm in London at the moment, do you fancy, you know, come up and take me round the town?” Which in fact we didn't in the end.

I went up and he was learning a script for something and wanted me to go through it with him but it was just fascinating, absolutely fascinating to talk to him. And he didn't forget you. I mean I saw him two or three other times and you'd turn up in a vast queue of fans and he would see you and go “Hello how are you?”. You know ? It was very nice of him. The giant. Absolute giant of twentieth century music.

4. What have been those elements of your musical training that have proved of most use in the exercise of your professional musical life today? As well as being technically competent, what informs your ability to successfully interpret emotionally charged music, particularly that seeking to convey life's dark side?

Ok, um, let me start by saying when I teach people to conduct, no, when I give a conducting lesson, you don't teach someone how to do anything, but when I give a conducting lesson, and I don't do it very often, but that's the only teaching I really enjoy. I mean I love teaching someone the piano but you've clearly got to be teaching them for a number of years whereas a conducting lesson could be a one off, on a specific piece or a specific problem.

I always start by saying I have two rules, (I perhaps shouldn't be telling you this as a member of one of my orchestras) I have two rules which is 'Tell the truth' no specific order and 'Listen'. They are one and the same really. And when I say 'Tell the truth' if you got someone in the orchestra and you're more likely to speak individually to a woodwind player or a brass player because they are all soloist, individual lines and they are doing something that in your head you think they can do this differently for me, and the other thing is it can be very interesting to wire a conductor up, or wire any professional up, you know a clergyman up whilst they are giving service but I'm thinking, I'm thinking, I'm thinking, um and you with this interest in mind will spot it within an orchestra when you think, "Well (N) is being very encouraging with that" but that's probably the best way to approach that because to be too critical the person may go the wrong way and it may actually get worse.

I mean I know somebody who plays a woodwind instrument in another one of my orchestras and I know with 'Dear (N)' and she is a darling, you have to be very careful how you approach it. Not that she is going to have a tantrum but if you over praise her analysis and in a wonky sort of way she does analyse it, she'll go "Oh my God he thinks I play that well. God I'll never play it as well again." And it goes wrong. You criticise something, not criticise but you suggest "Could you perhaps (N) play that a little louder or um, "I do think it's too staccato." because you've drawn attention to it, it becomes a problem.

So sometimes it's best to leave well alone. So the listening and the thinking come together but you're very, very much thinking with the people 'Is this going to work for them?' And if you've listened correctly, I'll give you a very simple example, if you've listened correctly to something what you will say if you are articulate is “Please could you do that.” And that person will look back on you and say “Well fair enough. He hasn't said anything silly, he hasn't waffled. I did play that out of time or whatever.” And you'll get a nice look and a nice look back and a “Sure (N).” Or you suggest something.

The ability to make people play something that, shall we say suits the emotion of the piece, whether it be, and we're talking specifically of the dark side, things that are distressing, but whether it be shall we say the other side of things where you are doing something that is very bouncy and fun, you know you might be doing a children's concert and the 'Teddy Bears Picnic', a very good piece of music, it all comes from your being, um. And it comes from an element of showbiz where you have to put that across because if you are in the right mood and your arms and your body are feeling right you can achieve it. And this is something that people who don't conduct it’s, very very hard to sense because it is a physical thing, it is a physical thing you can create.

We were doing 'In the Steps of Central Asia' as you know on Saturday It starts with a clarinet solo then there's a horn solo and the clarinet solo is in

one key the horn solo is in a different key, I mean not a weird different key but I can tell that our particular horn player was a bit worried. I could see in his physicality and on the previous rehearsal he hadn't quite hit it in the middle and I thought 'Hmm I think he's going to not get this note in the middle, it'll split, he'll then find it half a second later but it will throw the audience and they won't enjoy it, you know it won't transport them.' So I just said to said person "Shall we just do that opening again, just so you feel happy?" Because, again that's telling the truth. "Should we just do that again?, Would you like to do that again? To make yourself feel happy". And again the person said "I'm just, I'm not feeling quite myself tonight." So I said " Fine, so you're all right on that?"

But I went home thinking 'Wish he'd said', "could we do it?" then he'd feel happy and we'd all feel happy. So come the concert I thought what I mustn't do, this won't work on tape because it's visual, what I mustn't do is give a beat that goes... (gesture) because that is hard and its at an angle, so I just do a relaxed ... (gesture) and it's very easy,

I mean I have conducted the 'War Requiem' and the piece you are fascinated by and the 'Matthew Passion' I have conducted and when you're performing it (I did them when I was certainly quite young) you mustn't go out there and try to suggest that you have some great interpretation. Certainly from my point of view, something like the 'War Requiem' (which actually I have done

at the Albert Hall) um, is, is just so well constructed. I mean like all Britten you look at it and you go well, I don't know. If you know the opening is it 7/4? It's all so correct that you don't feel you need to say anything, you just need to do it right, you just need to do it right and then it comes across**.** I mean if you 're the great man and Britten's... I heard it on record review them saying I'm afraid still the Britten recording is the one that people respect most. Which is fair enough because Britten was famously a good conductor and a lot of composers aren't.

And uh, conductors and musicologists get themselves in a state going “Well he did it like that.” and you go “Well, he couldn't really conduct.” So it's not fair to say that what he does is exactly what he wanted because he might turn round and say “Well actually you know I just didn't know how to do that.” An orchestra is having to be aware of what the conductor is setting out...It has to be, It has to be what you are doing with the conductor. I mean the uh, yeah. I mean people talk with orchestras of honeymoon periods. You know a conductor comes in and, um, you come in and they go, “Well he's very nice.” and they get used to you, um until the extent of things like even attendance. “(N) is good, he'll be all right, he'll sort it out, he'll make sure it's rehearsed.” And then, you know, so you might then need to create a little bit of tension, a bit of a tantrum, um, you know to make that happen with the group.

But the business which is relevant to your question is that whether they like you or not, if the conductor knows what he is doing, um exactly, I mean, you know you don't have to be the greatest musician to look and go “Well he doesn't know what he's doing. I don't know why I am at this concert, I don't know why I am at this orchestra.” But if the conductor knows what he is doing and there's faith, the orchestra then just say 'that's his interpretation'. It has to be, it has to be otherwise there would be a mess otherwise, everyone, everyone, I'm not saying that people would play out of time but, you know, if a, if people are fighting a phrasing, I'm not going to do that. Well you give up don't you?

There is a give and take, you know, you turn to a soloist and if you've not got any strong views and they say “Could we just, I feel I'd like to move that a forward a bit, is that all right?” You think “Oh lovely.”

5. What of your own life experiences do you bring to your professional life that have helped shaped you into the musician that you have become?

Um, God this sounds a touch smug. One becomes, this connects with one of your previous questions, you become much more humble when something appalling happens and you just go “ If I drop dead tomorrow I have been so lucky.”

I mean I was in my bank in (N), (N) and I'd just written out my paying-in slip and a very large blind man came in and he was fine, he had his stick and he knew where he was going and he walked up to the place where they ask you to queue and uh, I'd rather forgotten what he was doing, my mind was wandering and then suddenly it was his turn to go forward and he moved slightly to the left instead of going straight to the cashier and the cashier said " Oh, Mr So and so", she knew his name, I don't think he had a badge on, she said his name, "Straight forward Mr So and so." And then I heard and I thought 'God you are so professional.'

They are all probably trained to know this of course but she was so pleasant and he was obviously an intelligent man spoke and then she said " Right, now I'm going to count your money out for you." And did it all like that. And I just walked off and thought 'What am I complaining about?' You know, completely sighted, what have you. Everything takes him 5, 10 times as long, you know, extraordinary. So, you do, you know, you do become rather humble about that.

Terribly little things affected me. I mean my somewhat eccentric piano teacher at the Royal College of Music, she taught me a way of learning the piano. I wasn't, I mean I think I'm a pretty competent pianist now but I was a second study pianist, I'm always playing the piano now. But she taught me a

way of learning. And I won't hold this question up but one thing she would say with a new piece of music, she'd say “Well now can you play this through now ?” and I'd go “Well no, not really.” I mean I could have made a mess of it but that's you know, when you're Royal College of Music it's got to be rather better than that. She'd say, “Can't you play any of it?” And what she was really teaching me to do was teaching me to teach.

And I developed it in my teaching and I use it very much in the way I work. So she said “Well you can't play the last chord?” and I'd go “Oh yes, I can play the last chord.” and she'd say “Play the last chord.” “Then she'd say “Play it beautifully. Are your wrists right? “Really beautifully? Good. So look away, last chord done. Can you see that chord anywhere else in the piece?” And she'd put a pencil through all these bars. “Let's do the opening few bars.” And before you knew it she'd told you you'd nearly learnt the piece. She'd go “So that's the exposition, that's done isn't it? Same key, let's cross that out.”

I apply it to everything. And another little thing, there's two, one of them I share with my set-builders for (N) Opera. He, they're two of the most wise diplomatic people I know and they can have designers, young ebullient designers come up with all sorts of clever ideas and think, I'm overhearing them and I think 'If it was me I would have exploded over all this nonsense, these ideas', but they don't, they listen to it and they'll go with it, whatever.

But (N) once said to me, when he was building something, he said “My woodwork teacher at school taught me one little expression which was 'measure twice, cut once.'” And I apply that to almost everything. Before you do something think 'Yeah, let's just set this up, am I doing this the best way so that I'm not going to have to do this all over again?'.

If you saw my house you wouldn't say that. I think, you know, those little things you can apply in an orchestra, um and there are just lots of little things over the years I've learnt. Little things, like in an orchestra don't have lots of spare chairs about because spare chairs, (N) at the Academy taught me that, spare chairs make people think that someone’s missing. You know, tidy it up a bit, make it look smart. I mean, this you see this orchestra (N) and (N) set it up. Makes you feel good. You go into the room we're ready for action. And if you were rehearsing a choir don't rehearse in too small a room. If you rehearse in the right size room people, again slightly opposite, if people are missing people go 'Oh Golly, I'd better not miss next week, there's holes here, we want to fill this up.'

I would say in the world I am of conducting there's more psychology but you mustn't be clever clogs about it, you know. You need to have a realistic understanding of what’s going on, you know... People don't like it if you're in an orchestra,(certainly people wouldn't like it in a Parish) you know, that you don't know the people. I mean I know everyone in every orchestra... I don't

really try but I think, I think of it from my point of view, that if I was there and I kept being referred to as 'Second clarinet' or 'Double basses' and you think 'Well there's only two of us' you know, um and you do know, ooh people can be touchy, as you know people can be very, very touchy.

One of my orchestras which are in a bit of bad way, they're all such emotionally touchy and frail people and they're, you know, bless 'em, quite wet. You feel like saying “Get a little bit of gumption, a bit of backbone.”

I would now like to focus on the theme of the painful experiences of life explored in music.

6. What are some examples of compositions that you can think of that for you in particular address painful human experiences such as loss, desolation and isolation?

There are just so many things. I am lucky, I won't get too stuck on it because it's Britten again but I am lucky to have conducted Peter Grimes, in several performances in two different productions twice, one about 23 years ago and one only about 3 years ago. And, um, it's an amazing piece to work at in a rehearsal room. I mean when I work with Directors, the good ones, and that's something else, sadly the only ones I'm really interested in working with and you know, you have to discuss with a singer what all this means. The prejudice upon Grimes and this fisherman and the misunderstandings and

the odd-ball in society at that time, you know, when it was written and the fact that it brought Britten and Piers back to this country when they were conscientious objectors and living on Long Island and he read an account of this story 'The Borough', specifically the Peter Grimes story.

And, um, now a days I must say I, you begin to start listing pieces and say, actually there are less and less pieces that I feel very emotional about. You know, clearly in perfection terms the four Brahms symphonies. You don't really want to get involved in discussing them because they are just there. They're little gems, it's like looking at, you know, Staffordshire dogs or Wedgwood or a stunning view Borrowdale. You just know.

But on the other side of the coin, and this will make you, um... sorry I want to explain that when you're working at a piece, particularly if it is day in and day out and twice a year I do an Opera, I was, I mean I've done most of the Mozart Operas, and suddenly the radio was on in the car and I listen to all sorts of things on the radio, you know, lots of tripe as well, but you know I was listening and suddenly Radio 3 was on and Figaro was on and I thought 'We just must do Figaro again, we just must. This is just so wonderful.'

Actually then you get in rehearsal and maybe, actually this was a very, very good Director, but you then get in rehearsal and you're going over something

time and time again and the gilt goes off the gingerbread a bit you know. It's still a masterpiece and it is sad. I mean I often say to people, and I wish I hadn't heard this piece. I wish now was my first go at it. So, you also have a job of work to do. I mean I remember one of the, Joe Horowitz was very much still alive. One of our tutors at college said “Come on, get this out of your heads that composers suddenly become inspired. They probably become inspired because they're being paid money.” You know, that it's a commission. Even going back to people like Handel, whatever, people working for courts. You know, was it Earl of Chandlos And other, yes, unbelievable stuff. And Bach but they became inspired, something was triggered off by the fact that ”well, I've got to sit down and write this piece.”

But on completely the other side of the coin, as I was going to say is I was lucky enough to know very well (N) and, um it was just a joy to know him and I've recently become more re-acquainted with his music because we did a work of his, you probably know that he was a Quaker ? In his words he 'tussled' with it for many many years but eventually he was a Quaker.

He wrote a lovely song about John (George) Fox, the founder of the Quakers, um, and, um I mustn't get stuck on (N) because I could actually talk about (N) for ever. He struggled, I remember with (N), sitting, because (N) would always try and go out with the audience whenever I did concerts with him. I would say “(N), (N) they don't want to see you yet, they want to see

you when, “Oh yes, yes.” I remember sitting with him and he would say things like **“** What's all this about?”

And in fact his wife (N), who I saw really quite recently and a very sprightly lady in her late 70s. She left him because she said “I'd hoped I'd married a man and I married this man who wrote these jolly little tunes.” Well these jolly little tunes that he wrote with (N) are without doubt in my mind the greatest comedy writing of all time. I mean I think their writing makes Gilbert and Sullivan look like beginners. And I'll tell you for one very, very obvious, I think, reason is that every word that (N) wrote could be just a poem. You wouldn't need to have (N)'s music but equally every tune that (N) wrote, which, he was a 'tune-smith' par excellence, it could be turned into a little clarinet piece it could be turned into a you know, mini movement of something.

And when he came out of (N) and he, poor chap he'd been up there for 3 years then on tour, Edinburgh Festival, then Australia, America. He went up to their Suffolk home in a place beginning with 'M', I can't remember but it's not important and he always wanted to write an opera based on Perelandra, C S Lewis' Perelandra. Do you know it? Well this is Sci-Fi religion. Perelandra is, this will get you thinking now, is Paradise and Adam and Eve are represented by 'The Lady' and 'The King'. And there are C S Lewis

fanatics they're quite, the sort of 'Born again Christian' almost to a point of paranoia about it, it's great excess.

Just before (N) died and meetings with him we were thinking we're going to put this piece on. I mean we knew he wasn't going to be around but after he died his amanuensis, his personal assistant, we met at (N)'s cafe, Donald used to go to a cafe down the road, um, and he had remarried. And we started discussing, we thought, 'it's all a bit trite this'. The C S Lewis society of Oxford, this particular, this assistant did a talk on Perelandra and C S Lewis to them and they said “Why don't we put on Perelandra, concert, performance, whatever?” so this Summer I have just done that and we think musically, well actually all of it is stunning. It's stunning.

You wouldn't know the music at all but it is, I mean, uh, it's worth a thesis in itself actually because Weston, who is another scientist Ransom, he's taken. I'll quickly get over this, Ransom is taken to Perelandra by the Eldila, which are floating sort of angels. It all sounds bizarre but when you get start getting into it, you get sucked. And he's taken to Perelandra by, if you like, by the correct means. Weston goes in a spaceship and Weston represents the Devil. All the temptations and the lady of Perelandra, the equivalent of Eve she knows nothing. She asks questions like “Well what is village ? What is

friendship?" and Ransom manages to protect her from all the evils of Weston.

7. Have your compositions/performances ever affected the way that family, friends and colleagues related to you?

Well, very interesting, a little bit, I mean people get a bit nervous of it. I mean I've now got a nephew who's gone into music in a lot more light music way but my sister is always a bit, slightly, not supercilious but I suppose it comes out in a nervous way and she'll pretend that she knows what's going on when she really doesn't. I mean she's no fool she's got 6 children and half of them are Doctors. And my brother once said, when my mother said "You don't really (and this was when he was working) you don't really ever come to (N)'s concerts. " And he said, I've never forgotten this, he said " Well, (N) doesn't come and watch me behind my desk." Which seemed logical but then it was utterly illogical because well you don't watch people behind their desks but you do watch people when they're conducting and listening.

No, we're all at it on the whole, no he does come to my concerts if he wants to but I mean if you're doing quite a lot of concerts, I mean I don't do hundred's of concerts but if you do quite a lot of concerts, uh, my mother occasionally now, and she's in her 90's but people will rather irritatingly come

up and say to her “Aren't you proud?” and she's always got a really good answer like “Oh yes, terribly, yes terribly. I have seen him conduct a few times before.”

8. Have you ever felt the need for particular support yourself when creating/re-creating 'dark' pieces of music? If so what form has this support taken?

This is, um, the answer is not very often. Not very often because I enthuse about a piece of music, very often in rehearsal because you're, you're fresh to it then. You know what you're going to do but suddenly you're reminded of it because you conducted it lots of times and then I'm often more moved then, by going “Wow, isn't this amazing” (in rehearsal). But come the concert, sometimes, often people say to me how do I think it went? And I say “Well you'll think this odd but I'm not really listening. Because if I'm listening I'm not moving forward.” So you know, I'm starting a piece of music (sings)'Taa, lum' Ok what you mustn't do, and this may be quite interesting for you because it makes me, it does paint me or as a conductor a little bit more a job of work because supposing, you know, 'Brahm's Four' that opening phrase the violins played out of tune well, well, you know in an amateur orchestra that is so easy isn't it? I mean, you know, it's very hard. If they played out of tune what you mustn't do to the players is perhaps grimace, very easy to do, very, very easy to do but then of course they don't go on to blossom the next phrase.

You have to live in the present...you have to, so that you are going on and you think, 'where does this phrase go?' and of course, you know if someone's played something really out of tune I'll say, well “Yes, it was very out of tune.” But I can't be telling you really how well the whole thing went. Having said that (at the concert) on Saturday I know the best result was that everybody, and I mean everybody, played as well as they could have done, it was a total success from the point of view of the audience. I wasn't, I wasn't going home thinking 'Golly, I could have done that better, I started it too fast.'

You also have to have some tricks up your sleeve, I mean you've probably noticed that occasionally with the 'Sea Symphony' which I think you played in, well I've done it a lot, and I know that if you get to a certain point in the last movement before that vast all shifts, all C's, all that, is it D major? I think, um, well, it's so straight forward. Don't rehearse it, make sure you've done it the night before but don't in the concert go all the way through that to the end just for the sake of filling the time, just go “Thank you ladies and gentlemen.” I mean a lot of conductors, some that have been to (N), simply can't time their rehearsals and then that creates this tension. If it's a big symphony, then people are sold out in the afternoon... And there's also that feeling that you've said to your wife. “Oh, I'll be back at a certain time.” and then he's over-run by ten minutes, Grrrrr.

I would now like to explore the effect that the painful experiences of life explored in music can have on the way that you live your life day by day.

9 Do you find that seeking to interpret life's dark experiences gives you any better understanding of those who experience life shadow side 'in the raw' so to speak?

Let me see if I can just focus that. I have found and I'll say this (but please don't quote it in any way because it sounds a bit smug). I used to conduct at a choir in (N) and (N)'s a bit of a rough place, a new town um, and it was a very, very happy experience with this choir. They'd been on a downer with the previous conductor, the numbers had dropped and there was a rift with another choir in the town, typical, two choirs in the town fighting. It was so silly, it was like a 'Carry On' film. Anyway, we had a very, very happy time and they were pleased to have me there and it was socially very good and they had parties and little cabarets taking the mickey out of what we'd done in the concert. Great, great, ideas, um, but you had some wonderful comments from people and um, it was because they came out on a Thursday night and you lifted them, like maybe going to a church service. You lifted them into a place that they didn't know they were going to go to. They'd probably had a row with their husband, burnt the supper, whatever. It took them out of it.

And one Christmas, it's the nicest thing, well I've remembered it, a dear lady, who is still alive, a tiny little lady whose name is (N), wonderful name, and

she was a primary school teacher, and I mean she was absolutely marvellous. She sent me a card I think, one Christmas, that said 'To that wonderful man who makes us all feel young again.' Which was a lovely, lovely thing to say.

And we also had a lady in the choir who had a terribly disabled daughter, brain totally there, and her daughter enjoyed my rehearsals, um, with choir, as you know, it's often quite different, there's almost a little more comedy about it, which I enjoy and I mix the comedy in and get the job done. And she would come in, the mum had one of these fork lift trucks in the back of the car, you know and her husband had left her and very often the daughter had to be looked after by the grandfather, you know there was this pressure on the family.

But this woman was wonderful and she'd bring her in, was her name (N) ? Whatever her name was and she'd bring her in to the back of rehearsals and we would go and talk to them and we would have a perfectly civil, civilised conversation with her, but, poor woman, it was all moving and twitching and all, but you could hear what she said and she wrote me a poem, a poem, not me, a poem, which was called Jesus Christ the conductor. And she'd watched rehearsals and she'd compared perhaps preaching and teaching to conducting and controlling people, um and again, there was nothing with me but with her. Well she was a clever girl, a very, very highly intelligent girl and

she'd watched all this and she thought how interesting it was, again, from my point of view, it's rather more the rehearsal, you know, people, people, I mean.

I've had many letters. A dear friend of mine who sadly died of cancer quite a few years ago. I didn't really know her at all. She joined my first choir, I started getting these beautiful letters from her. She was possibly slightly enamoured by me but she became a very close friend and I knew her family, still know her family and her marriage was breaking up and in a sort of nice way, there wasn't animosity, they weren't working together. And she would write me these marvellous things and say, you know, 'rehearsing this is just so uplifting' and from me one of the things is because music is one's life and I think a lot of people don't realise this. Musicians are quite insular. You know, I'm always amazed, (N), he didn't start learning the cello till he was thirty and he plays *that* well and is always learning. Whereas we as musicians are just going on with music the whole time. You know you have a completely different job, you trained professionally and so many of the people... just one of a number of hobbies. Very, very impressive. And they come along to rehearsal and they just get soaked up by it and probably find time to practice. Music is not a luxury, it is an essential and if people are not music-making. there's something gone out in their life, that kind of importance...

Yes, so the business of the shadow is, if it makes any sense is these people who come along and it really does lift them up. And it's nice when people come up... I did a rehearsal for a friend of mine's orchestra, one, just deputised for him the other day and, um they were close to their concert. They were very well rehearsed and I'd been there before and so people come up to you, “How lovely to see you again.” and you feel like a visiting vicar. And you have to be careful because, you know again, you don't want to feel smug, you're just doing it. But a girl in the first flute, (N) she just, we'd had our cup of coffee and whatever I said, shall we, let's do this now, the last movement of the Shostakovich and she rushed up to me and said “I just want to say I always so enjoy your rehearsal.” and so nice and she said “ The others were too embarrassed to come up and say it but we are enjoying it.” I just said, “That really is nice.” because people don't always say that sort of thing.

People are a bit sort of self-conscious aren't they... They also think, because you see as a conductor you do have to be a show-off, you do have to be show-off and sometimes you know, like the song in 'Annie Get Your Gun', you know when the opening occurs and your heart is breaking, and whatever, you still have to go on and do it. And people think “Oh, well he's just cocky.” But you’re not. You get in the car on the way back home and your... You know and you get back at ten past twelve and you think I wish I didn't have to get up until, you know, twelve o'clock tomorrow morning but you've got to get up and do something.

10. Has performing such pieces rooted in life's painful experiences ever changed your own sense of priorities? Has it caused you to make any major changes in your life?

Oh there's no doubt, there's absolutely no doubt, I mean, there's no doubt that you, I think you do forget how much of a drug it is, you know in the nice sense of the word drug that you do. I mean in the summer I did have too busy a summer and I didn't quite realise it. And I was doing one of my Youth orchestras and it's very intense and it's for 8 days. And because it's youngsters, your rehearsals are starting at 9 o' clock in the morning, which means you're getting up at half past 7 and then you're having breakfast and waking yourself up and whatever. And there is a gap in the afternoon, and I was at one point during the week feeling so exhausted I thought I'm just, I'm just, (I've never done this before) but I'm just getting into my car and I'm going to drive an hour away from here and I'm going to ring up the administrator and say “I'm just really sorry (N), I just can't keep going and I just can't keep going, I'm just so exhausted by it.” But then when you have that period when you're not doing too much you start balancing it all out and going, 'yeah I do need it' and it makes you feel extremely lucky.

But I am organising a re-union on Saturday**,** my old school music department which has been incredibly rewarding. But it’s very interesting talking to all these people to find out the sort of jobs they do. Lots of them are still very heavily involved in music but of course a huge number of them are paper pushing and um, you know, you think 'oh, how do they do it and how

extremely lucky.' so yes it does really make you feel.... I'm quite lucky because I'm not married, you know, I don't want to be married, I don't particularly want a partner, its not a worry. But you know, you do look around and see people who think, you know, these reunion people, someone saying (well you know, parents were my main contact, would say things like), 'Yes well (N) did have three children with his wife, but she, they're in Cyprus now, he's got a new family of, two more girls and they're going through private education" and you go 'Why?' He's going to have these around for 20 years and got to still keep finding vast, you know how many thousand pounds a term? Being single, your perspective is different, because it has to be doesn't it? Because you organise your time differently... You can go in and you can close your back door and go, it doesn't matter that the bed is not made, but it is made.

I've gone off at a bit of a tangent because it is very important for your research but whether it be... I think I do feel..., I mean I've done a 'Matthew Passion' a couple of times and I did one and one which had problems which I won't go into, it just, there were some musical problems the continuo player was not really coping. And you feel such huge responsibility, is the word allegiance, to this perfect work, that if it's not going right you want to go "Sorry everyone stop, everybody stop and we do this again, now, we do it again, NOW!"

And I remember actually, strangely enough I remember with the concert manager of this lovely, lovely lady, inspirational, writing to, we sort of went through it, we almost exorcised the distress of why this didn't work and that didn't work and we should have learnt lesson. And she was such an amazing person. I mean, I don't think she's even remotely religious but I never known, but she is, you feel she is incredibly spiritual. And so kind. She had a way of ringing me up and always beginning by saying “(N) it's (N), is it a good time?” and I, it wasn't until years later that I realised what a lovely way to start a conversation because you could actually say “Could I ring you back (N)?” “Oh absolutely fine.” Um, I think you do feel, when they are great pieces you do feel privileged.... I think, I'm sure if it's all going pear shaped, you know it must be such a horrible place to be, because it's almost like sacrilege really, something beautiful is being destroyed before your very eyes...Luckily I don't get involved in too many of those this time. I think if there's commitment to something there's commitment to something, even if something might be a bit out of tune, you can tell.

I mean when I, I very rarely go to shall I say amateur performances of things now because you just look, you just look at the programme and you think, 'well that's a badly constructed programme, you don't know what you're doing. You know, that piece doesn't go with that piece, that doesn't work at all and why are you doing that?' Then you look at a timing of something and you think 'well that's too long, I don't want to hear that after that' and you maybe notice a soloist and you go, or you read something and it says there's

a soloist from the orchestra doing the viola concerto and you know that's impossible, it's never going to happen.

11. When immersed in interpreting, through the medium of music, these dark experiences of life, what affect [if any] has this had on your outlook on the world, such as a religious faith or world view.

Well, it's very interesting and I don't know what the statistic is but there are an enormous number of composers who set religious text that aren't religious at all. I mean the most modern and most famous of course, the most living is John Rutter who says that no he's, he but he just loves the text, um and, uh, and it inspires him, the text absolutely inspires him.

But for me, my point of view, I have other issues about church and religion, perhaps rather more basic things, um, but yes I am, I am inspired by the setting of text. A composer writes something, some wonderful lines and the shape of the phrase it does move me and I am most definitely moved but, this is not relevant to your question, but I slightly fight against it.

I mean when I first moved from where I lived because I'd lived, where I lived for 20, 30 years, and I thought, you know because I was head chorister at

the church for absolutely ever. The great hymn tunes of which I know probably thousands still make me feel good and the text makes me feel good whether it be the composer's tune like the Vaughan Williams 'For all the Saints' I mean it's just marvellous, 'Come down oh love divine' Down Ampney, they are wonderful and it almost a medical thing, isn't it? For a scientist to say " Is it the tune that is moving you? Is it the way, the shape of the tune?". I mean, I know there's been in research, great research into and a chord, a chord is something that makes you feel absolutely marvellous and you, I mean there was one, once, and I always said if you had to drop to dead it would be on the chord of (sings) 'Ah may we soon again renew with our', in 'Blest pair of sirens' by Parry and the way it leads in, (sings) 'la, ti da di' the sopranos come in and I remember getting sopranos to sing it over and over again and you know, how wonderful this is.

And I remember saying to a cellist, a very irritating woman (and I remember her name but I won't say it) um, We were doing Dvorak 8, the cello tune (sings) 'ba, ba, da, da dee' and we were rehearsing it and the placing of notes and um.. Yeah I was probably quite green, it was in Tunbridge Wells that I was rehearsing, and I was very excited by it and, you know, happy. And I remember saying " Do you know, if we rehearse this every minute of every day before the concert we would never be perfect would it?" And the cellos all looked at me as if to say "We know exactly what you mean." Because the whole point of it is we don't know how perfect it can be,

perfection is not to be obtained. If we, whatever we're rehearsing tonight, did a phrase and a little red or a green light went on and said “That's it, you got it.” we'd all go “Oh.” What do you do next. But as I did this with the cellos, a lady in the violas went “Why?” and she was a very aggressive woman. And, um, in those days, probably (even now I know I can wind people up by a certain arrogance) and so in those days I was probably impossible and I must say I know exactly what I said and what I said was “Well if you don't know why, I'm rather sorry for you.” and there was a little rustle of feet, but it was very rude of me.

12. When exploring the painful experiences of life in music, have you found yourself using any recurrent images or symbols? If so, could you tell me what they are?

Well, um, it's very difficult as a conductor because, obviously, you know, you look the same. I used to jokingly say “Ladies and gentlemen I'm looking at you and you all have your own individual television screens, whether it be BBC 1, BBC 2”, we all joke on this you see but nowadays it doesn't sound so good because there are so many channels and I said “But here I am in my own television screen, and of course I'm BBC 2” and that was when it had just come out, and I said “The sad bit is that I'm always this BBC 2 and I'm sorry about that, uh, and I can't always, you know, effervesce and give different faces.” But you've got to be very careful about honesty.

It's back to honesty and listening. You've got to, uh, offer things in the most normal, natural way. Opening of the Verdi Requiem you know, opening of Beethoven 5. These are dramatic statements in totally different ways but you've got to, it's got to be open. And again its more really of a physicality of allowing yourself just to play something, finding the right moment. I mean not starting too quickly, gathering the forces, not doing the inevitable thing that our Primary school and maybe Secondary school teachers did as the choir comes on. Usually the music teacher is more nervous than anyone else because are they actually going to come in, are they going to remember it?... But that thing when the teacher comes on and grins at everybody and tries to make everyone smile. Whether we did or not I don't know but you've got to be very careful of that, you've got to be very careful of that because it's got to be honest.

Alan Sybil, famous horn player asked it be read out (whether it ever was) at his memorial service, he said, I want to be read out, and I think it was, he said something like '30 years in the BBC Symphony Orchestra and only 2 decent performances'. He was a great wag and a terrible alcoholic but I know what he meant really because from my point of view I look at all the stuff I've done, endless tapes, most of which I don't listen to and I think I'd be quite distressed if I did. But, you, you, there are pinnacles you know and I have to say last Saturday wasn't exactly a pinnacle but it was a huge achievement.

It's back to honesty, it's back to honest about how you do something. I don't, I don't suddenly think of myself, think of something deeply emotional about it but I mean you are trying to think (particularly if it's, you know, a choral work), you are trying to think ahead of the text. But there are an awful lot of practical things. I mean the (N) Choir. You know, it comes down to people stuffed in there like sardines, and you go, when you've had to deal with a bit of emotional over here when the altos think they haven't got enough space. They are usually behind the basses. They don't like it at all...And the sopranos grumble because they're in behind the horns.

13. What role do you think that the arts in general, and music in particular, have in exploring every kind of human encounter? Can uncovering the darker side of human life, be seen in a positive negative or neutral light?

Oh absolutely no question whatsoever I mean, it might not be appropriate if someone has just been dramatically bereaved but I think it can help in, there's huge research on this, I know this, um in fact our first oboe on Saturday is involved with people with senile dementia It's a different area but there's no question that music can lift the spirit and sometimes a jolly good, a jolly good weep, you know, let the floodgates open if they're watching a performance. We've all done it, I've done it often in the most trite bits of music, something has just got to me. A great tune, a great tune can really,

really get you. I mean a (N) tune, um. One that always sticks in my mind are the railway station that have all been closed (N) yeah, that one always gets me going, always, I mean even now... and I've got (N) doing it on his own, which of course is even more genius because it starts on which ever drop of another hat it starts with (N) doing his monologue by air and he finishes and says, he says and the last line is “I agree with the ladies, the old lady who said if God had intended us to fly he would never have invented the railways.” So the audience applauds that so he says “So instead we've written a song about the railways.” and then he says, rather different, rather serious for us, and he's found the most beautiful train names, you know, Windmill End, Cocker-mouth to Buttermere, some of the Isle of Wight names on it, amazing... and beautifully rhymed 'And the sleeper sleeps.'

14. Can there be any mileage to be gained by the arts, including music, taking a contrary position so that rather than uncovering that which is destructive, seeks to uplift the human spirit by focusing on the divine, however that be understood ?

Oh I see, yes I think absolutely there's no question about that. Um, I mean the emotional, golly you've got my brain thinking about all this now. The emotional, um, people go to concerts for all sorts of different reasons and I suppose the most purist experience if you like is someone who buys, someone has a recording and sits at home and listens to a piece and hears it in isolation. Almost like a piece of pure art. If that person's happy with the

recording of it they just listens to it as pure art and are deeply, deeply moved by it.

Occasionally I bore people, I mean this opening scene in Perelandra it's just, it's about a ten minute scene, and its just a perfect piece of theatre, for a Director, for a performance, for a performer, for a musician. Its, its a perfect piece, um and that scene, um is totally engaging. It's not one where people are going “Oh Gosh this, the plot of this is grim”. I mean my mother once said, oh God, she went to a performance of 'Fidelio' well, you know, she's not a technically a listening musician, she's an interested musician and she didn't get it at all, you know. That Leanora's husband had been wrongly put in prison. But I don't think, absolutely don't think there's a need. I mean there are some works now and you just turn around and go “Well what the hell? Why did you think of writing an opera on this subject?” Crazy it’s not going to do anything for me. But I mean opera plots particularly really, have got crazier and crazier. But people still turn up to see it. People are still very, very interested and buy them.

But, I mean, you can go to the other side and, I'm a great lover you know of musicals. But you get too much of that and you go, uh its all just all saccharin and sweet and happy**,** happy, happy. I guess

It depends what's going on in your own life as well, doesn't it, what you are wanting to respond to...

But, you know, as a professional musician, sometimes you go and see something and I just go, 'Oh I know too much about this, I wish I didn't know it, I wish I didn't know how it was written, I wish I didn't know all the lines.' I'm afraid for me it very often disables me and sometimes I look at a thing and I think 'Well I don't really like that composer's work' and I can't imagine that this is suddenly going to be utterly different.

So again (Donald's got a good mention in this) Donald's piece was fascinating to come across it and find out how utterly different it is because, I think, I defy a lot of people who knew Donald but had no inkling to say that's Donald Swan.

Often I think that people who don't know a lot about music get a greater music experience, a better charged music experience than those of us who understand why it's done. If someone comes to a concert they, they're not going, like I am, 'The double basses are in the wrong position, if they were all angled slightly better they'd be able to see the conductor, it would all be much.... Because you know I'm very hot on this, because otherwise you know if you've got someone playing and they're continually doing that (gesture) or whatever, um, you know, they wouldn't be thinking about that and they're not thrown. You know, I look and I see the moment someone starts tuning up in that situation I think 'oh, this is going to be terrible, they can't even tune up, first oboe can't even give a decent A, um. On the other

hand you go to a Joshua Bell recital, a viola recital, I'm going tomorrow night, and its going to be perfect, its going to be perfect. And that one I'm almost a little bit like, well I knew it would be like that really, I knew you'd would be marvellous. So where do I go from that?... Isn't that interesting? It's says a very interesting thing about knowledge doesn't it ? About knowledge...

Thank you very much for agreeing to be interviewed.

Transcription 201

I would like to begin by asking you about your illness:

1. Could you say something about the onset of your illness. How did you first become aware that you were unwell?

First indication was I was very tired and I had fallen asleep as soon as I got back from work, in fact sometimes fell asleep at work. But then I just felt completely weak, couldn't eat and that's when I decided it was time to consult the doctor.

2. How did it develop?

Really the illness was caused because the prostate had swollen, this caused the outflow of urine to be reduced, which I put down to age, thought well, probably quite normal but it wasn't and this caused a back flow of urine which filled up the kidneys and of course caused damage to the kidneys.

3. Could you briefly describe the treatment plan? Was it subject to change?

Remember I had two sessions of kidney failure. This was the first kidney failure and I went into hospital and they said first thing we've got to do is to get you better, physically, we need to do an operation on your prostate, but

that can wait, the first thing we'll do is dialyse you, gently, we'll do an hour the first day, couple of hours the second day, three hours after four, four or five days then we'll start four hour dialysis.

This went on until they felt, well it looks OK. Then they did an operation on the prostate so that I could pass water normally again. And after a couple of weeks I was discharged from hospital, went back to hospital for dialysis three times a week and after a couple of months they said “Let’s try you without dialysis because your readings are very good. And I am sure you could have two years without dialysis at least.”

Well it was ten years before the next failure. Dr (N) thinks that one of the kidneys was working and the other one had completely given up the ghost. The second kidney failed ten years after 2004, yeah about 2004, 2005 actually, 2004 it was, yeah, but then I think that was possibly caused, no one knows for sure but I think it was the same thing I think there was a stone in the urethra, I mean I'm not a 100% sure but anyway the kidney failed and the same symptoms really, I was really ill, feeling really bad, fortunately I was going to have an operation anyway and when I went for the pre-assessment the blood tests taken were shown to a Doctor and they said “This is terrible,” so they got me in. And the next thing I was in (N) and again we went through process dialysis, slowly at first, couple of hours then up to the four hours,

after two weeks I was discharged and I started the dialysis routine of three visits a week.

4. What were your feelings after diagnosis prior to the illness developing?

Well the first failure I didn't know what to do I was completely lost. I didn't know what dialysis was, no idea, um, I was worried, first thing was who was going to pay for all this treatment I was getting in the hospital? The second was if this is it, I didn't realise was the kidney improved for me to continue life and I thought well there is the job gone I'll be going back to UK.

I was abroad when this was diagnosed, and I didn't really know what to do. My wife was in turmoil, she didn't know what to do with the dog. Anyway things resolved, my boss came to visit me and he said, I said “Am I expected to pay for this ?” And he said “Don't be silly”, he said “Part of your contract is medical”, he said “Anyway I don't think there'll be a bill from this hospital”. And there wasn't. So things gradually resolved.

Then I met my friend (who) was on leave at the time, who was a company pension representative for overseas staff and he said “Don't worry I can get you early retirement if you want on medical grounds, it's quite easy.” He said “You just go and visit the (N) doctor and he'll have a look at you and say

you're not fit to go overseas you can't work anymore." And he said "You'll get your pension". So that was a good relief for me.

But as it was, after two months, as I say, on this dialysis three times a week. The kidney was functioning. You had to take precautions, keep low protein diet and various other things but as I say it lasted for ten years. And I carried on working until my proper retirement date.

Then the second phase didn't really bother me at all because I had already retired. I suppose at first I hoped the same thing would happen again, that the kidney would start functioning again. I thought it was just a temporary notch. But I was told by one of the Consultants who said he said "Things were wrong" he said "I don't think this kidney will function again, better make sure that's your friend because you're going to be relying on it for quite some time." Which worked out to be true.

5. As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?

No I accepted it, once I realised that it wasn't going to improve, then I thought that's it. I suppose you wait and see if you get transplants or something. But that was a failure too because I went through the tests to see if you were fit enough for transplant but I still had prostate trouble. So that's where I was

going before, was to get this prostate sorted out so that's when they found cancer. When they did the TURP, they must have taken a biopsy as well and that's when they discovered I had cancer.

So the next step was radiotherapy. forty, I think I had forty sessions or thirty eight and that took me off the transplant list and I haven't got back on since because they want you to wait at least five years before putting you back on, you know before they put you back on the list, if your'e fit enough to get back on. But they won't consider you anyway for five, some people say seven, some people five.

Radiotherapy cleared up the prostate cancer. That's in abeyance. It's pretty low you know, one of the lowest readings they can get now for the check.

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

I just did it, um, I was in the golf club and when I went, it was quite a while before I went, Oh possibly not. October was when I had the second, um,

failure and I think I probably went to the golf club about February, March. Because I wanted to see if I could still be member, you know. I couldn't play golf because I was too weak so I wondered if I could sort of have a reduced type membership. But I just told people what had happened and one of the other gentlemen, his wife had had a transplant and so it was easy to talk to him because he understood what I was talking about. And we told all the others, well, you know the ones that I knew, I didn't sort of put a notice up and we just had a laugh about it because most of the others had something wrong with them. In fact we even suggested instead of us going to visit the doctor's he should come to the golf club once a week! And uh, would save the trouble. We had a very interesting golf club. Well the seniors you see didn't bother with the juniors.

7. *Did you find that your illness affected the way that family, friends and colleagues related to you?*

Well I don't really know because I don't have too many friends, except for golf friends because I've been overseas so long. And no-one ever mentions it when they write to me they just say “How are you getting on?” This sort of thing, in fact half of these have had Strokes and bits and pieces so in the end I'm better off than some of these, although I'm on three times a week, I can walk and I can talk so they don't really mention it.

Well, my wife, she just soldiers on and sometimes I think she wants to do a bit more for me than I really need, you know what I mean, 'fusses' a bit. That's about it a bit, but that's quite natural. She fusses if it means a trip upstairs if I forget my glasses. No, no, no but that's probably because I fell down the stairs once. I think now she says "I'll go and get it for him 'cause it's less trouble than him falling down again."

8. What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?

Actually I don't remember having any at all. Except my wife, of course, visiting me. And actually I think the thing that cheered me up the most was when I was in (N) and you know just after the failure and doing dialysis I suddenly thought, I've got to come over here three times a week, for dialysis', I don't fancy this especially, in the winter. So I'm sat working out ways, Should I move?' Because I had no idea there was a dialysis unit … (N). And then one day a lady came in, in civilian clothes, and they said "This is (N), she's in charge of the (N) dialysis unit." Oh! She said "You're being discharged tomorrow they'll dialyse you before you leave, apparently you'll be on dialysis with us. The car will pick you up at one o'clock and you'll come to our unit at (N)."

So that was really a high point. Because the thought of going to (N) three times a week. And that was really well a big relief, although I probably would have had to move, which I didn't want to really. Well I couldn't put up with that every day, not necessarily move to (N) but near so I didn't have to get the (N) and things.

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

I don't actually know anyone which, who is that ill really. The people I have known they seem to have got ill and died pretty rapidly. In fact one or two before I even knew they were ill. But at least it's simple to sympathise more with people because you realise that they are in a similar state to you, in a way, especially if they've got a long term type illness.

10. Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?

Yes, I think giving up golf, which was really a big change. That was my life really I mean four times a week that's about twenty five hours a week playing

golf and uh, we had to cut out the um socialising because of at least a couple, well a couple of, you know, trips a week. And then actually the side effect of the radiotherapy was to cause problems in the colon so this caused trouble with the toilet so I didn't really want to go out for a meal or anything because you just didn't know when you wanted to go to a toilet. When you want to go it's very sudden and this also looks as if it's irreparable. This business. Nothing seems to make it better. But the Consultant says as long as we can manage it we don't want to get the knife out and remove any parts of the colon. So it is manageable and I just put up with it. You just get used to putting up with it.

In fact I've decided I don't want any more treatment on it because it only makes it worse. So last year I didn't have any treatment at all because it only makes it bleed more. So I just sort of, unless something drastic happens, I shall just leave that part. I'm not bothering with that anymore and you just keep an eye on it yourself, more or less.

11. In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

Well I actually I feel grateful that I am in a country that you can get treatment for this. If you were in the States or somewhere and you didn't have insurance I'm afraid you'd just die I guess. And if you were in most African countries you'd die. So I feel extremely lucky that I am in this country and you get some good care and attention.

Apart from that I just more or less pretend there's nothing wrong with myself, just plod on as best I can. Keep to the golf club but I know I'll probably never play again ‘cause I'm getting on a bit, but I still walk. I always say to myself “As long as I can walk. I can take the dog out and he doesn't know what's wrong with me and that's good enough for me, you know what I mean?” He knows I'm pretty useless because he waits for me and he always turns round to make sure I'm still behind him, which is good.

I've always said my prayers actually, since I was a little boy. But this is because I was always, sort of, alone, if you know what I mean, well until I got married, sort of thing, I was an orphan since I was 6, I went to boarding school, then I joined the Air Force so it always seemed something to do was to say a prayer.

12. When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

Well, sometimes I say to myself “I'm a right idiot for not going seeing the doctor sooner when I wasn't passing water as well as I should have been,” but I thought that it was just age. Of course I had no idea that this could cause damage to the kidneys. Well, In fact I don't think I knew what the kidneys were for, well I think I had some idea but I didn't really have an idea.

And really that's the only illness I've ever had I mean I think I did twenty seven years with the Company and I didn't have any time off apart from this kidney thing, And I did twelve, thriteen years in the Air Force never had a day off for illness in the Air Force at all. Apart from flu I don't think I've ever had anything at boarding school.

So I just thought it was my fault really, self-inflicted, through not going to see the doctor. If I'd have seen somebody earlier they'd have probably done the TURP, which I had to have anyway, and it would have been ok. In fact that was the first thing the doctor said to me. She was a Dutch lady, she said “Don't you like the medical profession?” I said “I've got nothing against them.” “But if you'd have come a few months earlier”, she said, or a couple of weeks even, a month or so earlier because at the time she didn't know if one of the

kidneys would fire up again. She said “You're not in very good shape at the moment but anyway I'm sending you off to a colleague of mine”. Which is where I went. I just accept it, I say ‘Well that's life!’ If you’ve done lots of things then (things) would have worked out different wouldn't they?

13. Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?

I just think I see it as a neutral, it's something that's happened and I've got to put up with it. And as I say the golf was a big part of my life at the time and you just have to accept that's it, you're not going to play anymore. But on the same token, if I broke my arm or (had) done something to my hand or something I probably wouldn't be able to play anyway. So I just, in fact I don't go to golf club any more because that's the one thing I'm envious. When I go there I say it's always a lovely day, when I go. I don't go when it's raining and it always looks so beautiful. And I see these people going round playing and I really think I'd better get out of here because I begin to feel envious and you don't really want to. You don't want to sort of sit there thinking, ‘I could be out there’. In fact, I probably could, you know.But I can't really walk far enough to do nine holes cause that's two and a half kilometres, three kilometres, although I take the dog sometimes that far. But by the time I found my ball it would probably more like ten kilometres!

14. How do you feel about the future?

Yeah, sometimes you don't think you've got any future to be honest, you just think you're just plodding on, waiting for the next thing to go wrong. I mean when they said last year we won't put you on the transplant list, I agreed with the surgeon, actually because I didn't want this cancer spreading or flaring up again. I mean I had the treatment the first time I thought 'God no! What it'll do the second time?'

So, but I wasn't disappointed because I was more frightened of having the transplant and having to take these drugs. Although if they'd have put me on the list, I can't imagine getting a transplant for four, five, six, maybe seven, eight years by which time I would be 74, 75. They'd probably think "Well it would be a bit of a waste of a kidney on him at his age" which I would agree with actually. If a chance of somebody, you know up to 60 getting one or me at 74, 75 I'd much rather he had it or she had it than me because you've had your life. I mean when I look across and see little ones. I think "Gosh, this didn't happen to me till I was 63." Can you imagine it happening if you're 5 years old?

So I just feel well, I'm lucky, I had a good life up till 66, and actually now I enjoy things I mean just, you cut down your expectations. A walk along the front to me is a super day. You don't have to stay out all day, go home and if

we do go for a meal, now and then I pluck up the courage and I'm going anyway if I need the toilet, but I get a period when it's good.

Thank you very much for agreeing to be interviewed.

Transcription 202

I would like to begin by asking you about your illness:

1. Could you say something about the onset of your illness. How did you first become aware that you were unwell?

OK, um this was Eleven years ago. I was walking through the subway at Temple-meads station in Bristol to meet some friends, catch a train to meet some friends in Bath and this was about 6 o'clock in the evening and I wasn't due to meet them at 7 so I wasn't in any rush I was strolling along through the subway, which is a kind of marble, flat marble surface.

Suddenly there was an almighty 'Crack' like a gun going off and a searing pain in my left foot, my little toe, and I staggered to a chair trying not to, you know, trying not to cry and breathe deeply, breathing deeply, and I collapsed into the seat. Several people looked round at me and everything and I um screamed in pain. And this man asked me if I was all right and being brave as usual I just said “Oh yes, yes I'm OK” when I should have asked him to call an ambulance.

And I managed to get outside and get the bus home. Along the main road and got a bus home. The bus journey just seemed endless and I was in

agony. And when I got home I was in so much pain I could hardly make it up the lane to um, you know, to the house and when I got in I just collapsed.

And what had happened was I had somehow broken my little toe and the next day I went to hospital and it wasn't properly, it was x-rayed but it wasn't properly diagnosed because little bones like that don't show up very easily on an x-ray. They are quite difficult to read.

So being a Type 1 Diabetic this injury then caused the other bones in my foot to collapse, to deteriorate. That resulted in an infection and an ulcer the diameter of a two pound coin and about an inch deep.

I ended up with 16 broken bones in my left foot, every step I took was absolute agony. And it, it ... (it was, it nearly killed me, literally. So that was the onset.

2. How did it develop?

Yes, I had, I was under the care of the Diabetes Team in (N) who were very, very good and I had two six months stays in hospital for um, intravenous antibiotics and bed rest. None of which sadly didn't do any good, it didn't

work. I also had constant podiatry treatment. And, um that really didn't work either.

Trouble is I was lacking in upper body strength and unable to use crutches so I had to walk a lot, well I had to weight bear. And it was a real battle between me and the Podiatrist they'd say “No you mustn't walk on your foot, you mustn't walk on your foot” and I'd say “I can't help it I have to, I have no choice” So that was a lot of hassle. And also I was living with my Mum and going into (N) a lot which is a very, very difficult City to get around. It's hilly and all the streets all higgledy piggledy and overcrowded and the pavements are in a dreadful state. Pitch dark lighting at night. So that didn't help either. It just made things ten times worse.

3. Could you briefly describe the treatment plan? Was it subject to change?

Uh, not really no. The treatment was bed rest initially, intravenous antibiotics, industrial strength antibiotics, um podiatry, regular weekly podiatry. And after a while, um, surgical intervention which meant a kind of, what they call a 'wash out' so that the ulcer is cleaned out under general anaesthetic and some bones removed to see if they could find a poisoned bone. The problem being that poisoned bones don't just 'show up' they're not discoloured or anything like that, you know, you don't know which bone is actually causing

the damage. I learned a lot about medicine in general, you know, because I was observing it every single day. It got to the stage where I could have put my own, my own um IV catheters in my arm if necessary! That's another thing, I'm not, I'm lucky, I don't have an aversion to needles and syringes at all, you know.

The only thing that I really didn't like, that upset me about the treatment was seeing other people suffer and also seeing people dying in the ward. I've had about ten people die on me over the course of the last eleven years. One of them actually right next to me. So I know when somebody dies in hospital I know exactly what the routine is and what happens. It's not nice. It's the sort of thing that really does my head in. All that, I hate that. It's something you never get used to.

4. What were your feelings after diagnosis prior to the illness developing?

I just accepted it. Um, it's the way the cookie crumbles, I suppose, as the Americans say. Just get on with it, whatever it takes. I did my best to comply with treatment but under the circumstances, the physical circumstances it was fairly difficult. It was an uphill task. But I was aware of what I should do and I did my damnedest to try make it work, you know, sadly it didn't but, in the end.

There's nothing anybody could have done to make it better, me or any of the diabetic team. There was no anger or bitterness whatsoever. There never has been. I never thought “Why me? It's not fair and boo-hoo, I'm ill.” I've never thought any that. I've never done that and what's the point ? It won't make it any better and it's not fair on other people.

5. As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?

They've not changed at all, I don't think. Um, not as far as I'm consciously aware. I've lost my foot, which is a shame I suppose although in some ways I think “Good riddance to the wretched thing !” because it was, it was not fit for purpose in the end, it was doing more harm than good. So now I've lost it I just have to get on with it now and learn how to walk again on a prosthetic limb. I realised that this was it and there's no way out. The alternative was to spend the rest of my life sitting in a wheelchair totally dependent on other people and I refused to do that.

I don't need to (dwell on that). I'm too young and too fit and I don't need to. I couldn't bear that. I hate using the wheelchair as it is but the thought of doing that forever, oh no, no, no. I am absolutely determined to walk out of here like anybody else. And I don't see why I shouldn't. I've always been like that about everything, you know ? And if I have something to do, I'll do it, however tough it is. Yes I've always been bloody minded.

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

I told them right from the start. I was living at home with my mother anyway so she had to know obviously, I couldn't have concealed it from her and I wouldn't have done anyway. And she was really, really helpful, you know, she put up with me for the best part of eleven years, on and off because I was living part time with mum and part time down here. It's gradually got worse and worse until here we are. But friends, family enormously supportive. I've never concealed it from anybody. There's been, I don't see why I should, there's been no point, you know, the more I can tell other people the more help and sympathy I'll get, although I don't want sympathy .

7. Did you find that your illness affected the way that family, friends and colleagues related to you?

Not really, no, no um I am a very keen campanologist, church bell ringer, and um, one of the local churches that I ring at in (N), the ringing master there was, he would do what I call this old hen act. I would catch hold of a bell and he would say “Oh no,no I wouldn't ring that (N) if I were you!” and that sort of

thing, he meant well, he really did, but it got very irritating you know. If I don't think I can do something I won't do it and if I do something that's because I think I can do it and know I can do it.

The one thing I did find very, very irritating was when I was using a wheelchair more or less full time at one period and I'd be going around, particularly in Bristol people would, I suppose they were helpful, they would hold a door open for me and uh they would immediately, as soon as they saw me coming they would leap up and do this little what I call the 'boy scout's act', you know, “Let me help you there mate, here mate this one.” And I'd say “No,no,” and it would get on my nerves and I felt like saying “Look, if I want help, I'll ask for it.”

I'm always trying to do things myself, you know ? And I still do. I won't ask for help unless I really need it. I appreciated their good intentions but it's negative, besides which I needed to sort of experiment and see what I could do for myself, you know, like opening doors and things like that.

8. What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?

Uh. Two of them stand out. One, my Mother who was very, very supportive indeed of me. She was always there and uh you know, she let me stay with

her and uh, she was always there to talk to, that kind of thing. So, um, Mum, yes, very, very much indeed. And, uh, also my cousin, uh (N), who is now sadly dead. He was about Mum's age something like that and he too was very, very supportive when I was in hospital. He would come in regularly with big bunches of grapes and books to read, things like that. He was very good.

And the other support of course was (N). Yes (N). About two months ago I went through a period of really serious exhaustion to the extent that just to exist I was scraping the bottom of the barrel and I was just right down to the last drop that I had. And (N) was there for me, you know, to help me, to cheer me up and to do shopping, to organise things that I needed, you know she was. She put up with periods of violent vomiting and she was there to uh, to ensure and sometimes insist that a doctor came out to see me. And she kept my spirits up, you know. I couldn't have got through those two months without (N). I really couldn't. And she's so important. I gave her a card with more or less what I've just told you written on it actually. So I don't knows how important she's been. If she's opened it she realises but if not, no I don't think she does. I wanted her to know.

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

Not really, no. I mean when I was in the hospital in (N), I used to see the same people on a very regular basis and uh, I would talk to them, a couple of them I've actually made solid friends with and I still know them today. One especially, (N), who is ... is a Diabetic and he was the chapel organist in (N).

I'm keeping a day to day diary on my experiences and I want to get it published. Either in book form or to a newspaper, something like that. In order to help other people who are going to go through this after me, you know and to inspire them and that sort of thing. And from maybe from a selfish point of view it maybe promotes me as an author and a writer so. It is a very therapeutic thing to do. Yes, yes it's quite important. And um, hopefully, when I'm old I will be able to read it and look back on it in years to come. But I'm hoping that this diary will be an inspiration for other people. You know, and it's not the end of the world.

10. Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?

Well, um, I wouldn't say major changes, no. Once I've learnt to walk again on my prosthetic limb I'll just carry on as normal, you know, as long as I can still work with boats, sail and ring church bells and walk normally I'll be happy. I'll have all I want. That'll be fine. And as long as I can keep my home in (N) as well which is very, very important to me, then that's fine. I don't think any

major changes are going to happen or be really necessary. Having to use the wheelchair, that's definitely temporary as far as I'm concerned.

11. In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

It's increased my Faith without any doubt what so ever. I feel I've been given this unique opportunity to get my life back, you know and I feel in a non-religious sense 'born again' as it were and instead of being a helpless, happy, bouncing baby I am a grown adult who knows what's out there and wants to get out there and enjoy it. And well at the end of the day well what can I say ? Except “Thank you God for everything.” Mm, I don't know what it is, whether it's me or God or both but I've been made better, been given this chance and I'm going to grab it with both hands and lap it up. I have to.

12. When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

Um, when I was, what was I, twelve I think it was, um I had a torsion of the right testis, you know where the cord twists around at an angle of about forty five degrees upon itself, cutting off its own blood supply. And the only

remedy for that is immediate surgical operation. And I was in hospital for ten days and I learnt the meaning of the word bravery in that ten days. You know, I was in an awful lot of pain and I remember it was about 10 o'clock at night waiting to go to the operating theatre and Dad was with me and a couple of nurses and I had never, ever at that stage, been so frightened in all my life, you know, I didn't know what to expect. But once I got upstairs to the theatres I was too interested in what was going on to be frightened which was actually good, but you know, I was in so much pain I wanted to scream and cry but I didn't, you know, I just put up with it. Because I thought, what's the point ? You know.

13. Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?

Very, very positive without question. There is no point in doing anything else. You know, it's not going to get any better and it wouldn't be fair on other people, especially the people who are trying, you know, treating me. It's got to be positive and I want it to be positive because the alternatives are just too awful to think about. I wish it hadn't happened. Of course I do but it has and I have to deal with it, you know. So I know it's not been easy and I know it's not going to be easy but the really tough part is still ahead, When I get my leg, I've got to learn to walk on that. That's when the really tough part is going to happen and if anything goes wrong it's going to be about then, something I think like that. Then it'll be round about that stage I think. But

then I'll be so close to home anyway. All I'm thinking about is getting back to (N) as soon as possible, you know. It's gorgeous, I have everything there.

14. How do you feel about the future?

Very positive. I'm comfortable and successful. I've got a lovely place to live. All I want now is a pet dog, for exercise. I'm going to get myself a Tibetan Terrier as a reward partly for being ill all this time, you know. I really, really want a pet dog and it would do me good, not just emotionally but physically as well. I'll take him out for exercise and enjoy looking after him.

(N)'s not so sure about this dog by any means but, she's not happy about it Bless her. I think I deserve it to be honest after what I've been through. Yeah, whether my landlord will agree is another matter but uh, I hope he does. Mm, mm. Very special, particularly with this type of dog, a Tibetan Terrier is fiercely loyal and they are absolutely lovely animals. They'll do anything for their owners, literally, they will literally die for them if need be. No they are wonderful creatures, I love them.

Thank you very much for agreeing to be interviewed.

Transcription 203

I would like to begin by asking you about your illness:

1. Could you say something about the onset of your illness. How did you first become aware that you were unwell?

Well it's five and a half months ago and to be honest I don't know what happened. All I know is that I'm in the hospital, in a bed and that's all I knew for some days. I knew I had a lot of people thinking about me and praying for me, so it seemed just to go on for time immemorial really and (N) used to come up every day for me, all that time he's come every day and I don't know what I would have done without him.

2. How did it develop?

I had um, it just came on as far as I know. *She was in The (N) nursing home,* Oh was I ? *and it was a Bank holiday weekend. There was a minimum of staff on duty. There were only nine total staff and they weren't necessarily medical staff. I called in at about 3 o'clock Sunday afternoon and I could see my wife was in serious distress. I tried to contact a medic, a medical attendant, and it took me some long time to find him at the extreme end of the building. And I said, "Have you seen my wife?" And so he said "No, somebody saw her this morning and she was all right." I said "Have you seen her now? "I said "You'd better come along and see her and in fact you'd*

better get the doctor as soon as you possibly can." He said "I will contact the doctor and I will come along and see your wife." He came along into the room where (N) was and he said, the doctor, I've told the doctor and he's advised me to get in touch with the paramedics.

The paramedics came within a quarter of an hour. Took one look at my wife, took a reading and phoned for the emergency ambulance with flashing lights to get there as soon as possible. She was then in a state of unconsciousness. When the paramedics, you know, took the readings they were very, very concerned and when the ambulance arrived they got her into the ambulance straight away. They said to me "If you're coming behind in the car, keep behind the ambulance to get there as closely as we do, this is a matter of great urgency."

She went into A&E and after an examination there she went into Medical Assessment and then straight into (N) ward within a day or so. And that's how her bronchial pneumonia, her bronchial pneumonia started. The whole fact remains that if I hadn't visited my wife that afternoon – she would have died. Now you know why I don't remember. *I went to The (N) after the Bank holiday when some staff started to come back and had an interview with the matron and the manager and told them what I thought of their service.*

3. Could you briefly describe the treatment plan? Was it subject to change?

I was in (N) ward. I don't know what they did, honestly. I'm not helping you very much, am I? *They gave you lots of oxygen.* Oh yes, lots of oxygen. I was on the oxygen thing, that's right. Well, I think that was about all that they did, oh except tablets. Yes medication and oxygen, and I was on oxygen for a long time. *She went into (N) Ward, I think it was on the 4th June and came out on about the 20th June I think. Then you went up to (N) ward.* Lots of physio, mostly that's what I had, trying to make me walk, that's what I couldn't do see, being in hospital all that time. It was four and a half months then, its gone up to five and a half now.

4. What were your feelings after diagnosis prior to the illness developing?

When they told me I was trying to blame everybody, I think, I don't know any, who to blame really. *I'd like to just say one thing, that when she came round and she wasn't, she was completely disorientated for at least 2 weeks.* And I didn't well, *and after that time, when I came in she said "I want you to sit down here a minute (N) and tell me why I am here," and that was the day when she 'came back'. So she didn't really know much about the first two or three weeks.* No, no I wanted to know why I had been so ill, yeah, that's true. I was a bit angry, not with you. *I've never known you to be angry in my life*

5. As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?

Oh yes, I'm still, I'm still, I don't know why I've gone all through this. I don't know at all. Um, it has all changed. I mean now I know I'm on the way, I'm ready. I hope I go home very soon and I know (N) does. *I think that* w*hen you became aware of what had happened to you and what was being done for you your words to me were that you were so grateful so much attention being given to you.* Oh yes, they did. *It was absolutely wonderful. She tells me this, she says every time I came in they'd, you know, I've only got to press this and they come, you know.*

Every time I went home, I used to give a bulletin to my children on the main land, and I used to write it down and sometimes here so that I knew what I was going to tell them. I've got a book at home a diary, you know, of all the reports, you know, *Still there. But I mean to say, that's was what I had to do because the children were so interested and being on the mainland. They have been as supportive as their jobs would allow them to do and all that.*

We are held in people's thoughts and prayers. Where do you go Monday? *20 Minutes meditation.* Oh meditation, that's right. *About 20 of us in a circle see.* (Lovely) Wednesday as well you see ... *Well on Wednesday I (N) and I run the Matins service and afterwards there's the 10 o'clock Communion service. Anyone else who cares to come, there's only about a dozen or so.*

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

Yes, I didn't have time to, no it wasn't, was it ? It wasn't kept quiet was it ? My illness. I was missed. *They wanted to know where you were. So they asked me. This is how people got to know about it. The fact that I wasn't there and you weren't there. You're a regular attender a the church services and when you're not there they say "Where's N?" And I had to tell them.* There are all the cards up there. Oh, that's my Birthday ones. *They've been terribly supportive really.*

I was nearly in tears this morning, I haven't told you that yet, I was in meditation and somebody said "You've been doing this so long now." It's been so long. Going every day and staying, you know, for hours. I wish you could stay. *Put their arms round me, it nearly brought tears to my eyes, yeah.* That's a long time, every day. *It's a wonderful Christian feeling, a family feeling.* Yes, yes fantastic.

7. Did you find that your illness affected the way that family, friends and colleagues related to you?

Well they all had prayers for me. Well the family of course, they came, well when they could but um, there were other friends that have come quite often. I think they all sort of felt, of course there must be some in (N) that don't know me, but the ones that do have felt um, haven't they? *Well they know what a caring loving person you are. How you look after everybody. You're always looking round for people that need a bit of assistance if they're not well. You're the first one to ask newcomers in the Church if they're coming to have a cup of coffee at the end, always.* That's right. Yeah, I do, I do. *People know that.* I ask people if they are new or if they live in (N). And if they say "Oh no, we've only just moved in." I ask them to go, well, take them round for coffee and get to know their names. I've always done that. I haven't done it lately.

8. What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?

Well (N), of course. Yes, it's always him. Um, he always... Well yes the Church. All the Church people and all their prayers and (N) comes in and says, you know, and then when he came in and told me about (N) and (N), that's the two that are down in (N) ward. I could hardly believe it. They were very dear friends, well they still are, (N) seems to be okay. I think (N)'s better isn't he ? *I think so yeah*. *Yeah, they talk quite well. He has a laugh and a*

joke. And talked about a new car even. Oh yeah. *And of course if you remember the accident they had to cut a hole in the roof to get them out so I said "You won't need an open top!"*

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

Can't see how it can. But I suppose, (N) would know about my illness. Oh yes, she used to ask about me before it all happened. She probably did when (N) went down and saw her. They are very close you know, and she would have, yes she would have... and who else? *We've got several friends that are, we've got a close friend in the (N) ward whom I've been up to see and the first thing they've said is "How's (N)?" In the midst of their worries.* She had a (N). *It's quite amazing.* Um, how about, oh... *You thinking about somebody in hospital ?* No she has been in hospital, um (N)'s wife. *You mean (N), you're talking about (N)?* Yes, my Daughter-in -law, she's just had a hysterectomy. *She had a hysterectomy.* She's just been in hospital but she still rung and asked how I was, so you know. I think everybody when you're in hospital they all sort of gather round almost. She couldn't work for six weeks or something like that. It's a nasty operation. *It seems to me that it's when you're really ill, not much is said prior to that but suddenly you realise*

the value of this person. You suddenly get warm feelings that you want them to feel how you feel. Yes that's right.

10. Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?

Only to live as long as I can when I get home. I've seen that book. *You've been reading that.* Oh yes I have been. Yes I suppose that is. *Nice to know.* Give it to me a moment. *Perhaps this is a more important one that...* I'm showing him this, I haven't shown him this. Well I've read that one, well reading that one, 'When I Awake', that's a book with little bits of scripture, I seem to remember.) *It's really a book for people entering into a more Spiritual way of looking at life and how to find quiet.* But this, this is some of (N)'s favourite prayers. I read these first, then I read that. I've had time to read. Have you done any more prayers that you want to write in there? *Yes.* Well you'd better take it home. *No I'll leave it there till you come.* Oh.

11. In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

Yes, yes. Those books, talking with God. Yes. Well that's it really. Well there's nothing you can do really, other than that, talking. I think w*e are very*

grateful, you know, for myself, I know you can scrub this off the tape when the time comes but what I mean to say I'm very conscious that God has been with us right from the start. Right from the time we left The (N) he was with us. I'm absolutely convinced of that. He has been with me on all my journeys and kept me out of trouble but he brought you back from your bronchial pneumonia. He brought you back to me, And my heart trouble. *Yes all those stages we felt him with us all the time.* Yes, that's true. *It' has been quite an experience really.*

Yes, yes. I mean to say I get a very great opportunity every Wednesday with (N). He and I are very often just on our own for Matins, you know from half past nine till ten. And we both talk to one another about our inner most thoughts. Very nice. He's been through such a terrible time himself with (N). With (N).

12. When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

I wish I could remember all these things but I can only seem to remember the bad things. Um, the um, the sort of hallucinations and all that.. *I was going to*

say she had terrible dreams and hallucinations that worried me terribly when she came in., when I came in and she told me about. They were awful ! *I had a full band in here marching around. They were so clear to her, you know and very worrying but the doctors explained to me that this was the sort of thing that happens.* I kept saying Why ? Why ? That was my word. I didn't want it, they were awful. There was no reason. When you opened your eyes again everything was okay but then if you go and shut your eyes you got another one. *They got rid of them (N) the day that you said to me "(N) why am I here?" I shall always remember that all my life. But that was a signal to me that she was asking a sensible question again which I hadn't had for at least two weeks.*

Yes, yes. I mean I used to go to bed, go to sleep and dream but it wasn't just nice things. He'd say try to think of something nice before you go to bed, *Happy holidays,* yes that's right, but I didn't. It was always, it must have been the illness I suppose.

13. Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?

Positive ? What was that ? But there again, I don't know that they taught me anything, not really, um as you say the nasty things were really nasty but they've gone. *It must, it must have been awful for you when you were fully hallucinating, it's a very worrying time because you weren't with us.* No I

wasn't. *I don't know, you know, I'm thinking about that you know, can a person think Spiritually when you're in that state of hallucination?*

I would hate anyone else to have to go through it. *It's really difficult to know how you can break that barrier at that time. I really feel at those times when I came in here and I came 10 o'clock in the morning till 10 o'clock at night that you just couldn't break through that barrier, you couldn't get a word of any sense and it was ... okay know whether spirit can talk to spirit in these circumstances I don't know but I went through the motions, I went through the motions.*

14. How do you feel about the future?

Um, come to see me in about a fortnight ! I hope to be home and I might be able to tell you a little bit more about the future but at the moment that's all I'll look forward to. *She is positive in her forward thinking there's no doubt about that.* I did my walk this morning. I walked round to the gym and back. The physio said when I got back “Jolly Good”.

Thank you very much for agreeing to be interviewed.

Transcription 204

I would like to begin by asking you about your illness:

1. Could you say something about the onset of your illness. How did you first become aware that you were unwell?

Well sudden and um, I wasn't aware until ... I don't know how many days later it was but um, until I found myself, in, you know in the Cardiac Unit. But I remember nothing of the um, onset or of being brought into hospital. Or anything. It's just all gone as has anything about the immediate post admission period just – completely non-existent. Um whether that will come back or not, I don't know. No I can't recall anything of that what so ever. I can't remember the ambulance coming or anything, you know it's gone. But whether that was ... so what I suffered at that time I've no idea.

2. How did it develop?

All I know is that it was unforeseen and very suddenly. I was just at home and it all happened, I'm told. I mean (N) would be more than willing to help you on things. What I mean is what actually happened I've no recall at all. It's a total wipe out.

3. Could you briefly describe the treatment plan? Was it subject to change?

Well the treatment plan, I think I was on Cardiac Unit for somewhere between a week and ten days, and then I was transferred up here. Initially I was upstairs I think and then downstairs. So I've been on (N) for, um, this will be I think my 4th week.

4. What were your feelings after diagnosis prior to the illness developing?

Well there was no diagnosis I mean the condition struck me and I didn't know anything about it, so there was no medical appointment to diagnose any underlying condition before, it was out of the blue. I know I had a heart attack but I couldn't explain to you in any more medical detail. Cardiac infarction isn't it ?

Yes, so I had one of them. Unbeknownst to me I mean I was completely oblivious of anything. Now whether that's because I didn't experience it or whether it hasn't gone into memory at all is another question, I don't know the answers to that. I can't separate the two possible reasons why or whether it was a combination of both I just don't know. I just don't recall anything, I don't recall coming into hospital or anything.

5. As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?

Um, well it's a surprise, I don't think I'll put it any stronger than that. I haven't said “Oh my goodness, you know, did that happened to me?” I mean it is, it is a surprise in as much as I always thought I was reasonably fit. I'd had no, um signs that I might be afflicted with a pre-existing condition so from that point of view when told and when registering what it was yeah I suppose I was a bit shocked. And um, it was probably, it was probably the immediate time and immediately afterwards greater shock for the family than it was to me because I was quite oblivious of what happened. I was in no discomfort or anything, you know so.

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

Not beforehand, knowing obviously, there is the usual family to advise afterwards, immediately afterwards and then the news has obviously spread out round the community and friends since then. But yeah I mean making sure that everybody was posted, other than the immediate family, is the last

thing on your mind, but those around you at the time. I mean since that um, initial, uh, day on which I was taken ill, obviously the family were the first to know and um subsequently close friends and it has gradually spread outward. So I suspect there's a goodly number of people that now know what my current situation is. Yes that's what friends are aren't they ? Friends and acquaintances, you know.

7. Did you find that your illness affected the way that family, friends and colleagues related to you?

It's difficult to answer because I mean your own perception of what's going on is changed because of what you've been through and pills that you may be on at the time and all sorts of things. My perception of the situation is that, no the family hasn't changed its view of me or… I mean it's just accepted, it's just one of those things that befalls you and thank goodness it wasn't more serious.

8. What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?

Well in terms of family support, I mean that's been great, I mean close family, wife, sons have done as much as they possibly could have been expected to do. I mean the nursing staff by and large have been, um supportive. I won't

say universally and to varying degrees you know, within that um, spectrum of support but I've received good care whilst I've been in here, by and large.

Sometimes I've felt frustrated with what's going on and thinking 'Oh for goodness sake if you did that in a slightly different way you'd be able to do what you've got to do and get it done' sort of thing. I think one of the things that's really got me in here has been um, when you're in process, in training of doing something and because there are other times uh, there are other calls upon nursing staff, they wander off and do something else. You know it might be a quarter of an hour before you're attended to again and at times that's got to me more than others depending on how comfortable I've been and what distractions I've had available at the time. And particularly you know, things like how cold or warm you are, you know, how comfortable you are.

Um it's been at times, and I wouldn't want to over-rate the number of times that's happened but it is an on-going observation when I think that some of the staff could be more focussed on what the task is. That seems a harsh criticism. Yes, if they asked me I'd tell them exactly the same so it's not that I'm sharing something with you that I wouldn't share with the care team. If they wanted to know what I felt about the treatment. Yeah if I have an opportunity, I mean I think there are feedback systems aren't there before you're discharged ?

I mean the other observation is um, the lack of much availability, I mean I am sure it's there if it was really needed and is called upon. But the lack of routine availability of um any of the medical team, Junior or more Senior Doctors. I've seen very little in the wards of that sort of 'bod' since I've been in, certainly in the Rehab Unit. In terms of our day by day needs then the care team has on the whole been pretty good.

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

Gosh, I don't know, um. I mean it's easy to, after a little while, to differentiate between those immediately around you who are iller than you are yourself, um some of whom are difficult, some of whom are not difficult. But even for those with difficulties it is often underlying medical cause or medication that they're on. So yes, you stop to think about those, yes certainly and you worry about how they are, particularly if somebody has gone downhill whose, who happens to be on your ward. And you think 'they're suffering more than I am' so hope they get better soon. You seem to in your own mind, rightly or wrongly, do a running order almost of patients. It's very natural after a day or so to get a grip on people's individual circumstances which covers everything from obviously their medical condition and how serious or how not serious

that might be towards things like what sort of family support do they get. Um are they reliant on elderly people to come in? Do they have local family members, which not all the more elderly patients have? Many rely on sons, daughters, grandsons, granddaughters who might be distant and not immediately available and you sort of identify their sense of unavoidable isolation from the family. And (you) certainly feel a degree of sympathy with them if they haven't got somebody at the end of a phone who can just pop in every day and that sort of thing.

10. Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?

That's a difficult one because I don't have perfect recall of all the decisions that I'd made prior to my admission. For instance, if, you know, I couldn't remember that I'd decided to put in for early retirement um, in, you know the past few months so uh, the fact that that's been granted came as a complete surprise to me but a great relief. It's a lot of near term things, stuff that I was doing in maybe in June or July that's gone, June and July um, early part of August that is just blown away and (N) says “Well, you know we did that” or so and so said that would be all right. And I'd say “Well I just can't recall that at all”. That's the frustrating thing. I mean you've just got to live with that and make a joke of it and be cautious in what you say and where you say it and to whom you say it, (so) you don't make some awful faux pas, you know.

And that's quite a slow thing, piecing the immediate past together. You know remembering what I planted in the garden, and things like that, uh, it's just gone you know. I'm sure when I get home the visual images will prompt a lot of recall but it's that sort of stuff, stuff from further back. My friends, um yes that's not too bad, yeah locations not too bad but it's just those I would say the last few months hasn't been implanted in deep memory and is therefore not available for instant recall.

Fortunately I am in a position where I can say to Anne “I can't remember that, you'll have to go over that.” and she's very patient in rebuilding things for me, and I dare say that will take quite a while to fill in all the bits that I don't know you see. That's the frustrating thing, you don't know what you don't know. I mean she said something to me this afternoon and I said “I just can't, no I can't comment on that I just don't know.”

11. In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?

My Faith and what's in it I think has been a source of considerable comfort and practically a source of considerable support. I mean I know that my own Church family have been thinking of me, asking of me, supporting (N) in many ways that they can. I have had a number of visits from my clergy team. I mean (N)‘s been in, (N)'s been in, um (N) and (N) have been in and it's

been lovely to maintain contact with them and it's helped things get back to some sense of normality. Catch up on the gossip!

(N) and (N) have certainly been great comfort here on occasions when they've popped in and they've brought something in for me even if they are just passing through. Yeah it's been really good. To remain connected in that way and to know that people are thinking of me, caring for me, praying for me and in practical ways that she, coming to see me and just saying hello for five minutes, you know, it's wonderful. And knowing that the wider outside immediate world is still ticking on, and just trying to catch up with what's going on, you know. Like it was um, Harvest, well it's Harvest Supper tonight, you know, well there'll be some, I shall be able to catch up on the gossip tomorrow when (N) comes up, you know just stuff like that is just being able to touch base and know that people have got you in their thoughts. That's a great inner comfort, yeah.

12. When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?

Well, uh, it's been a surprise, I mean I won't say a shock but it's been a great surprise that this sort of affliction has actually struck me because I had no indication. I've always been reasonably fit and active, um, had uh, quite a

high powered and onerous job at work and really had no indications that heart might be a problem to me. So that's the real blinder when you think, ‘Crikey why didn't I…’? I mean I don't know statistically what percentage of people are aware of a heart condition before something manifests itself but certainly in my case… I mean I used to be quite a keen walk guide, easily walk from (N) through to, well (N) you know in a day, no problem. So sort of through (N) and up over the top and through the forest so no, no real indication that you know, my ticker in any way was ... It is a bit of a shock and sometimes and even now I have to remember even now because since the, since the cardiac arrest you know, there's been no signs. I mean I've had no chest pains or anything.

Well it was a bolt from the blue, a surprise. Certainly a bolt from the blue I think for (N) you know, because I had had no chest pains or shortness of breath. Totally unexpected. Yeah I've always sort of eaten a sensible diet, done a reasonable amount of exercise, walked to and from work everyday. Well I seem to have done most of the things, I mean I'm not a lover of, you know, normal things that tend to do you less good. So I guess it’s just one of those things, maybe, maybe stress. I don't know 'cause quite a lot of stress involved with work, there was in the latter parts and um, I don't know, I don't really know, can't put it down to anything. What really tipped me over the balance.

I don't know but obviously some of the stress factors, mostly, well all of the work stress factors, you know have been now removed, because I am told that I am now retired so the knowledge that a) I don't have to go back to work and comforted b) by the knowledge that financially that's not a problematic thing for us, which is a great comfort, yeah. I shall, I shall enjoy my retirement. I think between now and Christmas will probably do enough (adjusting) and the prospect of not having to trog to work through the midst of January is something that I shan't be sorry, to ... be in work at 8 o'clock on a January morning, yeah, which I've done now for 40 years, however many year's service it was.

13. Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?

I'd say at the moment it was neither positive nor negative. I'm still too close to the nuts and bolts of the illness and the care that I've received since then. I mean I think I need a month, maybe two months at home when a different perspective will be assembled and I'll be able to reflect more meaningfully. Whether I can remember what I've experienced in the last six weeks in two or three months I don't know, but if I do, I think that will be the period of time when I'm back in my home environment.

I mean this is a uh, well the nights are nice and quiet I mean being on the ward you know, all day you're never quite sure what sort of a day it's going to

be, whether there's going to be a quiet one, whether there's going to be a crisis, all sorts of things you know, the unpredictability um. So yes, um, it will be nice to have a period in the home environment where it's um, stable and peaceful. It is at times the lack of feeling that you have any control over what's going on around you and that can be trivial or it can be something quite major and significant, um. But I think that's what's probably troubled me if anything has, you know really feeling…. I mean I've always been, I won't say a control freak, but because of the job that I did, one had to be pretty much in control of the situation for a number of people. So I guess that's something that I have to come to terms with but it won't be hard.

14. How do you feel about the future?

Well, optimistic because my predicament isn't worse than many, I'm mobile. They tell me that my, you know, my heart is okay um, at the moment. We've got to ask the focus questions about, you know what about, the longer term etc how I should care for that. But yeah optimistic. Mentally I'm feeling you know, good, positive, looking forward to getting home and sorting a few things out there. No I don't think there anything else I'd like to add. I think I've hopefully I've made sense and what you've got there is a sort of coherent answers.

What I will say I think in having the Christian structure within the hospital has been a great comfort. Seeing you, seeing (N), um, the Sunday gathering,

yeah that's been a good fixed point and a much valued fixed point in the weeks. I mean I think it’s only a couple when I've been considered well enough to come to chapel on a Sunday but yeah the knowing that that support mechanism has been there is something that has been good to know, that you've been around. No its true, its true because I mean we uh, we knew most of the people who worked in the chaplaincy team um, before now so yeah it's been very comforting, on a, yeah, comforting and nourishing on a Sunday.

Stuff that has been floating around my head in the last six weeks you know, most of it is just rubbish that has to be discarded now. But to know that within this crazy existence, um, both personal one and the organisational one, there are a number of fixed points that you can tie your rope to has been a great comfort, yeah.

Thank you very much for agreeing to be interviewed.

Taped transcription 205

.I would like to begin by asking you about your illness:

1. Could you say something about the onset of your illness. How did you first become aware that you were unwell?

It started out with a straight forward hip replacement, um, which then got infected and after seven days the whole thing burst open and I was back in hospital. Too many veins now were not working so I've had to have antibiotics given me through the neck. I was pretty soon on my third neck injection. In time I was hoping to be able to take my antibiotics orally once again.

2. *How did it develop?*

The infection developed, it came from the operating theatre, they thought it was in the cement. They had to then remove the hip that they'd just put in and keep me in hospital, because then I had no hip so I was then bedridden and they kept washing the wound or the hip out and, until they tried to clear the infection. This been going on for thirteen Months.

3. *Could you briefly describe the treatment plan? Was it subject to change?*

Well the treatment plan has been, over the months, to, once the infection has subsided, with the antibiotics and the microbiologists to fight the infection. And then it was a case of waiting till we thought the infection had cleared, fitting a new hip and then going back to square one. Unfortunately it's not quite been as good as that for me. This will be hip number three. Two hips already that they've put in and had to take out because the infection then came back again.

4. *What were your feelings after diagnosis prior to the illness developing?*

Well I thought that it was a straight forward hip replacement which would go as well as um, you know. It was going to be quite straight forward and there would be no problems. I had to totally adjust to what's happened, and it has very much sort of interfered with my life because I look after my sister who has had a Stroke.

5. *As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?*

Have my feelings changed? Um, Oh Gosh, how can I think about that? Well of course they have because the whole thing has interfered with my life and because I am relied on with my sister um, so it's meant that it's changed my

life. And of course for my brother. I mean they are both in their 80s and I am now the only driver so I do everything on that scale.

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

I did have no choice at all because then I had to put all sorts of things in place like carers for my sister. And when you walk around with a bright pair of blue crutches it's pretty obvious that something is drastically wrong. There's no way I could be private about this. Oh Gosh no, no.

7. *Did you find that your illness affected the way that family, friends and colleagues related to you?*

Um, the only thing I can say, I mean yes, everybody keeps saying or said, you know, it shouldn't have happened and how sorry they are for me and you know, sort of "How are we coping ?" But we've done very well, the three of us. There is only the three of us left in the whole family. But it's certainly not something I could have hidden from anybody.

8. *What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?*

Yes, uh, there was (support) and mainly from the nurses in here. They have been brilliant every day. I was told by the surgeon 'you would hit rock bottom at one stage' and that happened actually a couple of weeks back and the staff were absolutely top class. I just woke up one morning and said “I can't take any more, this is it.” I don't know what happened but that happened. It didn't last long, only a day. And the first person that came in was one of the auxiliaries, Brilliant! And that was it “Come on (N), you know, we're going to get through this together.” She knows my name because she was here when I came in a year ago. Yeah.

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

They do, um, but because it's the type of illness that it is then, you know we've um… No I find people, yes of course they feel sorry for me of what's happened and that. But it's not like a mental illness or a, you know. It is a very visible illness, yes, very visible. My nickname is 'Hip-less'. It's my nick name, Hip-less.

10. *Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?*

In my life personally, no not really. Luckily enough I've got a good team of people that I only have to lift up the phone if I want to know something. And as I said previously, I've carers put into place for my sister. I've now got a driver and very very good neighbours for my brother and sister because my brother can't drive, he's losing the sight in one eye. So he hasn't driven for two years.

11. *In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?*

Oh that's never altered, that will never alter. In fact every day I lay here and I look at, people won't be able to see this, but through one window I can see a tree and I look at that tree and more often than not my prayers go to that tree. Yes, yes and then if I look out that window I can look across the countryside. That's very important, yes.

12. *When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?*

No, uh, yes it did a couple of weeks back where I just felt that I just couldn't go on any longer with just laying here with no light at the end of the tunnel and then it turns round and then there is light at the end of the tunnel but you've got to help yourself to get there. You can't rely solely on other people.

13. *Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?*

Well it's been very positive because of the infection that I first encountered, you know, through a very straight forward operation and it's been with me rather a long time so I could never look at it negatively. But because of the effect it's had on my family, it's caused disruption.

14. *How do you feel about the future?*

I am looking to forward to it. I've promised my sister that once I'm up and I can walk then I will take her on holiday. That's a huge carrot, isn't it just. It's for both of us because she has to keep as well as she is with her Stroke and she now wants to go on the new Queen Elizabeth. Because we were on a cruise in July for three weeks and we didn't get back till the 8th of August and I was in here on the 31st August. It's a bit like being on a cruise in here without going anywhere. Scenery doesn't alter very often.

Thank you very much for agreeing to be interviewed.

Taped transcription 206

.I would like to begin by asking you about your illness:

1. Could you say something about the onset of your illness. How did you first become aware that you were unwell?

Basically I discovered a lump when I was in the shower one day and I was obviously quite worried about it because I had previously lost my mother to breast cancer, and I thought it might have been something to do with the birth of my son who was about 6 months old. But I spoke to my husband about it and he sort of urged me to go to the doctors and I decided that was the right thing to do.

2. *How did it develop?*

Basically I went to the doctors I think the next day and my GP was very honest and said that she didn't think because of my age that it would be anything nasty and told me that she'd just see me again a couple of weeks afterwards. And so then I went back again a couple of weeks later and the lump was actually still there and she said “I'm not sure I like the look of this”. So then I was then followed up with a hospital appointment and a mammogram and an ultrasound and basically ended up going for a biopsy in future weeks and that's when they discovered that it actually was cancer.

It was probably about six to eight weeks I think between the initial finding of the problem and the biopsy. Quite a while because they didn't think it was anything nasty because of my age. It was a really worrying time.

3. *Could you briefly describe the treatment plan? Was it subject to change?*

I was booked in, I think to have the operation to have the lump taken out and they told me that when they did that they were going to test my lymph nodes to see if it had spread. And they actually can do a test when you are having the operation done to see if the cancer spread. They like put a dye in. They done that and it had actually spread to three of my lymph nodes. So I ended up having about fifteen or twenty of them taken out on the left side of my arm. And also when I came round from the operation, they sort of told me then that it had spread but they were going to have to do further tests to sort of see how bad it was.

Um then obviously I recovered from the operation and then I started on my course of um six months chemotherapy. which I guess was where we bumped into each other. I did, um go to the full 6 months of that chemo'. I was due to have radiotherapy but because I had chosen to have a mastectomy after I finished my chemotherapy I didn't actually have to go through with that.

4. *What were your feelings after diagnosis prior to the illness developing?*

When I was sort of waiting to find out, I just felt really obviously scared and just worried about the children and just more worried about all my family really because where we had sort of been through it before with my Mum. Um just sort of worrying if I wasn't going to be around anymore um.. But when I actually got diagnosed, I just sort of obviously felt scared again as well but I just felt like I could deal with it better because I knew then um. And I sort of felt like I had to be strong for everybody else really to a certain extent and sort of say 'Oh I'll be all right" because that is the way I kind of deal with things really, sort of "I'm okay". So that's kind of how I dealt with it really even though I was sort of shocked. I went through, sort of different, loads of different emotions feeling really okay one minute and then obviously in tears the next. So I was like that for quite a while really until I got my head round it a bit more.

5. *As you think back over the course of your illness, have those feelings changed in any way? If they have, could you tell me how?*

I think where I lost my Mum to cancer, I think it was my worse fear sort of after losing her that I would always get it. And once I did actually get it I sort of feel the worst thing that could actually happen to me has happened. And then, I don't know, I just kind of felt got really strong throughout and just thought I can sort of get through this. And, I don't know, it was just strange

and really my life sort of carried on as normal with all this going on around me. It's all a bit of a blur, it's basically feeling normal in the middle of all this chaos.

I would now like to focus on how you feel your illness has affected other people's perception of you.

6. Did you make a decision to go public about your illness to colleagues, friends and others beyond your immediate family? If so, what helped you make up your mind?

I did tell them because obviously with the children and things, when I was going for tests and hospital appointments I needed help with the children, so I did choose to tell everyone really, all my friends and family. I can remember coming home and sort of saying to my Dad and obviously he was devastated 'cause we lost my Mum with breast cancer. And I can also remember like feeling worried what everyone was going to think of me when I was doing the school run and things like that. All I could think about was 'Oh my God I'm going to have no hair – everyone is going to know I'm ill' and even though that's like the least of your worries that was one thing that really worried me.

The children are too young to understand what's gone on really. (N) is, um (N), (N). When we came home that day when I'd been diagnosed, my husband took my daughter upstairs and I sort of sat my Dad down and told

him. But we decided that we wanted to be as honest as we could with my daughter so I remember (N) took her out for a drive into the park one day and just sort of told her in a sort of child friendly way, not to worry her, that Mummy was going to be losing her hair because she was going to have some medicine to make her feel better, and sort of just trying not to scare her. She's really a little worrier our little girl and we didn't want to frighten her or anything and think that anything was going to be awful happening to Mummy, but we kind of wanted to warn her that Mummy might not be the same for a little while.

7. *Did you find that your illness affected the way that family, friends and colleagues related to you?*

I don't, with my family and close, really close friends I don't think it did affect the way they treated me because I've got a very close circle of friends around me. And again, they were all with me when my Mum was ill so we've all sort of got a very close relationship. But, I suppose through my own paranoia I did always think if people were looking at me and sort of whispering behind my back, even though I don't know if that ever went on, but it's just a kind of natural thing isn't it? People talk don't they? And I think people obviously did but I never felt like I was treated particularly differently really.

8. *What have been the main sources of support to you during this time? Was there any support that was especially helpful in your worst moments?*

Obviously my husband and my children have really kept me going and made me laugh at my weakest moments. Like laughing when I've got no hair. And you wouldn't believe it, but we've had some really funny times really, shaving my hair off, which was my worse thing, when it was all coming out. But actually it was really funny doing it and actually felt really liberating to get rid of those last bits of hair and sort of feel free from it really. Honestly, I was dreading it and I'd come home that day when I'd got my wigs and it was just all coming out in clumps and I was really dreading it but really my husband just made it into something funny. I know it's really hard to believe but he shaved it off and we like shaved these really high bits over the ears and mucked around with it and it was actually funny. And I think I was really worried that it was going to upset me but it actually ended up being a relief to get rid of the last bit and think 'Right I can put my wig on now and I can feel relatively normal'. I know it sounds bizarre.

So humour was definitely one of the supports then. And obviously all my friends really supported me and obviously my best friend being one of the chemo nurses was really there for me up in the chemo ward. She's been brilliant that I can just ring her up any time I've got any questions. It's like I've got her on tap really, she's my best friend. We've known each other for a long long time. It's just so bizarre that obviously we've ended up having to be in this way together. Because I know it obviously really affected her the first

time that I went up for my chemo. She actually specifically worked that day so she could give it to me but I know it was a really hard thing for her to do, probably worse than me having it for the first time, for her to see one of her good friends sort of like that. It must have been really hard for her.

I would now like to ask you how you regard the significance of your illness and its impact upon the world.

9. Did you feel that your illness had an effect on your relationship with others who are unwell, both in your public role and your private encounters?

I think so because obviously when you are going through something like this, you do talk to other people obviously who are going through similar things and um I feel like a lot of people have dealt with the illness and kind of had worse side effects than me. In a way I feel like I've kind of got through it okay – if that makes any sense? I feel like, I used to feel like when I used to go to chemo. A lot of people were down, obviously because of what they were going through and sort of saying about all their side effects. And because I didn't seem to suffer with many of those I was kind of more upbeat so I sort of kind of feel like my story perhaps lifted other people sometimes. Because when you think of chemotherapy, you think you're going to be sick all the time and you're going to be really ill and not everyone does get like that I mean. So I think sometimes my side of things could, uplift people who were just starting their treatment because just to know that it wasn't all going to be doom and gloom and really bad.

I think my age was a positive factor in all this definitely, and also that the fact that I just had the children to look after. Although I had the support, I still had to carry on and try and do things with them because I am a bit of a control freak and I find it very hard to let things go. And I wanted them to keep me going, even though I had people offering to help me take (N) to school and do things. I wanted to do it. I wanted to just carry on as much as normal as I could 'cause I felt if anyone took over from me then I would almost just crumble and that would be it for me then. They all thought that I was mad but I just did it!

10. *Has your illness changed your sense of priorities? Has it caused you to make any major changes in your life?*

Yeah I think it has. When we were going through the illness like as a family, I did sort of sit down with my husband and we did kind of have lots of long chats about everything, “What if this happens and what if that happens?” And we did like make a conscious effort to be a bit nicer to each other at times when you might bicker over silly things. And just also just try to enjoy things more and not like let the daily life get you down. Obviously it does sometimes, but try not to let things get to you so much because really doing the dusting or the hoovering or whatever isn't really that important, it's about sort of being together. I know it's corny. And also we sort of said that we want to do holidays because I do almost feel like a sense of urgency now because

no one knows what the future holds obviously, but I kind of feel like I've got to get things done while I'm well. I've got to do this, I've got to do that and I do kind of feel a pressure almost to try to cram as much in now as possible, just in case.

We're thinking of planning a holiday soon really. I mean usually this time of year anyway, obviously you can feel a bit low after Christmas and everything. Anyway but I really feel like I need something to look forward to now and obviously after the past year everything we've sort of been through it would be really nice now I am sort of feeling, you know, more myself again to have something to look forward to as a family like a treat for us all again.

11. *In the context of your illness and recovery so far, what effect [if any] has the experience had on your outlook on the world, such as religious faith or world view?*

It's a tough one ! I mean I don't really have a Faith as such – I do believe in something um, not really sure what it is. I don't know. I think I've got a lot more compassion now for people but then also in the next breath when people really moan about nothing I find that quite irritating now. I think, you know there are so many people going through worse things that I find the general moaners in life really do irritate me now. Yeah so it's made me more compassionate with people in some ways but less so in others I think.

I don't know what I believe in, well, I don't really know what it is. I mean it's awful, but when you are in like a crisis in your life, it's just like you want somebody to help you. And I don't really have like I say any belief as such, but I do like to think there is something um. And obviously sometimes it's bad because you sort of feel like you're only asking for things when you're in trouble but that's what happens isn't it for a lot of people?

12. *When thinking of your experience of illness within your life, have you found yourself using any particular words and phrases to make sense of that time? Have these been images or words about anything in particular: loss journey, pain, blessing, darkness?*

I've never really felt like that to be honest. I've just kind of been sort of setting short time scales of like – right I've got to get through this bit and I've got to get through that bit. And now I've sort of come to the end almost of my journey of treatment and everything I just kind of feel like, when I look back I think 'Oh I can't believe all that's happened really !'

I suppose 'Light at the end of the tunnel,' that's all I've been aiming for is the end all the time getting to the end of it so probably that would be a good phrase. But to be honest, not going on about the kids and stuff but with all the hospital appointments and children it's just like getting through each day

– it just goes by so quick that there's always something to do that you don't actually get a lot of time to think. It's sort of being capable with life going on around you and trying to be normal as well.

13. *Would you say that on balance you have been able to see your illness in a positive, a negative or a neutral light?*

Probably neutral I'd say because at times I feel like it is positive because it's sort of made me feel a lot closer to my family because we've obviously talked about things in a lot more depth. But then obviously I do feel a bit negative about it as well because it's always at the back of my mind 'Will it come back?' and that's the only sort of worry really with me. And I suppose every person that goes through this wonders that. So it's sort of up and down, there is good points and bad points really.

14. *How do you feel about the future?*

I do feel really positive even though I am not the most positive person all the time. I mean because I feel so well, I kind of think in my mind that I'm not going to let this beat me you know because I feel good and that's a sign to me that everything is OK. Obviously I worry about the future, but then like anyone, can go out and get run over by a bus. And you just think that it's just because I've had cancer it doesn't mean that I'll die before anyone else dies. You've just got to think about it in a real logical way – anything can happen to

anyone. So in a way even well people should be trying to cram everything in their lives because no one knows what's around the corner. It does make you realise, and it can be obviously quite frustrating sometimes for people but, yeah, I think it's definitely made me a stronger person, definitely.

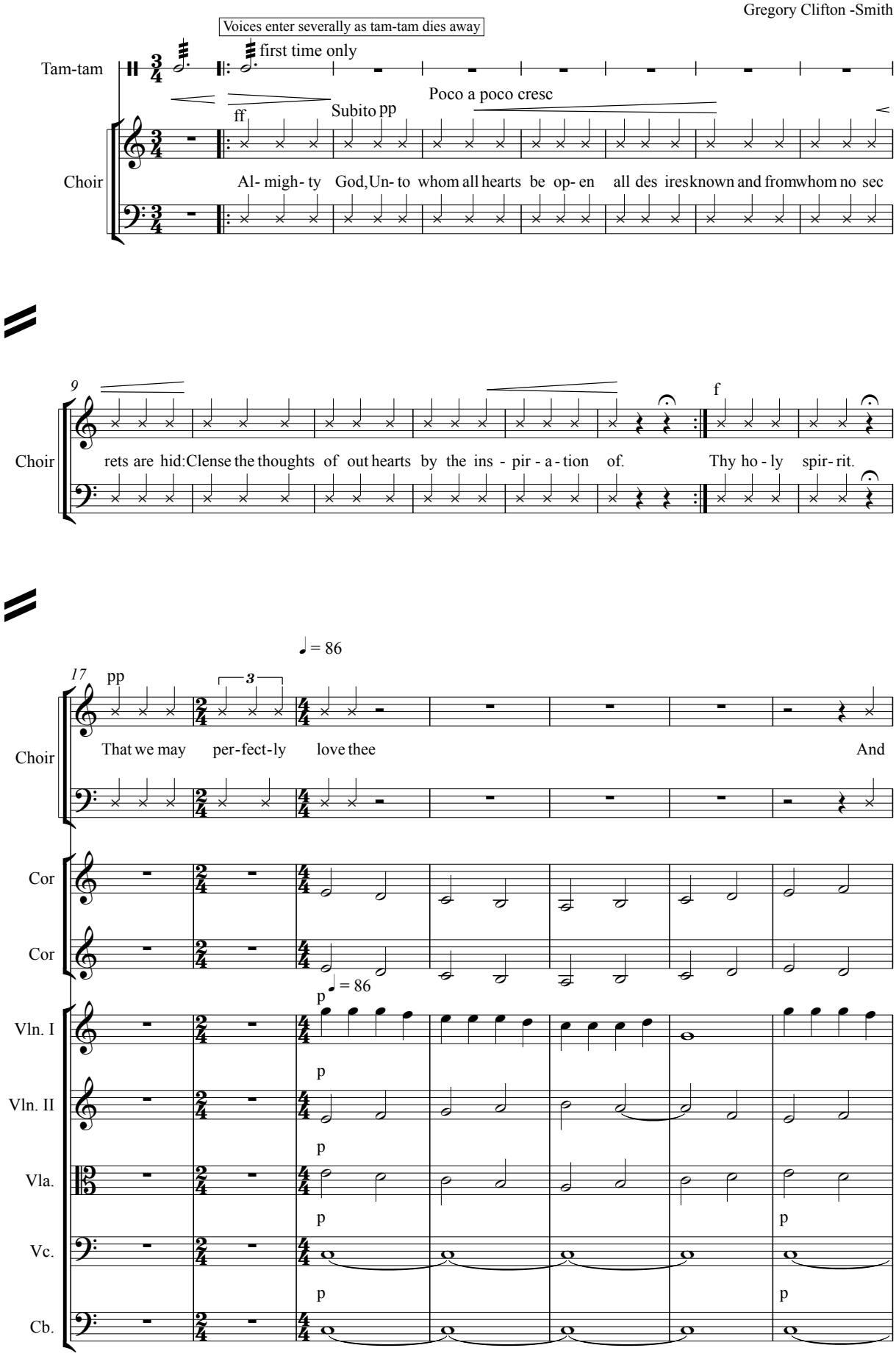
Thank you very much for agreeing to be interviewed.

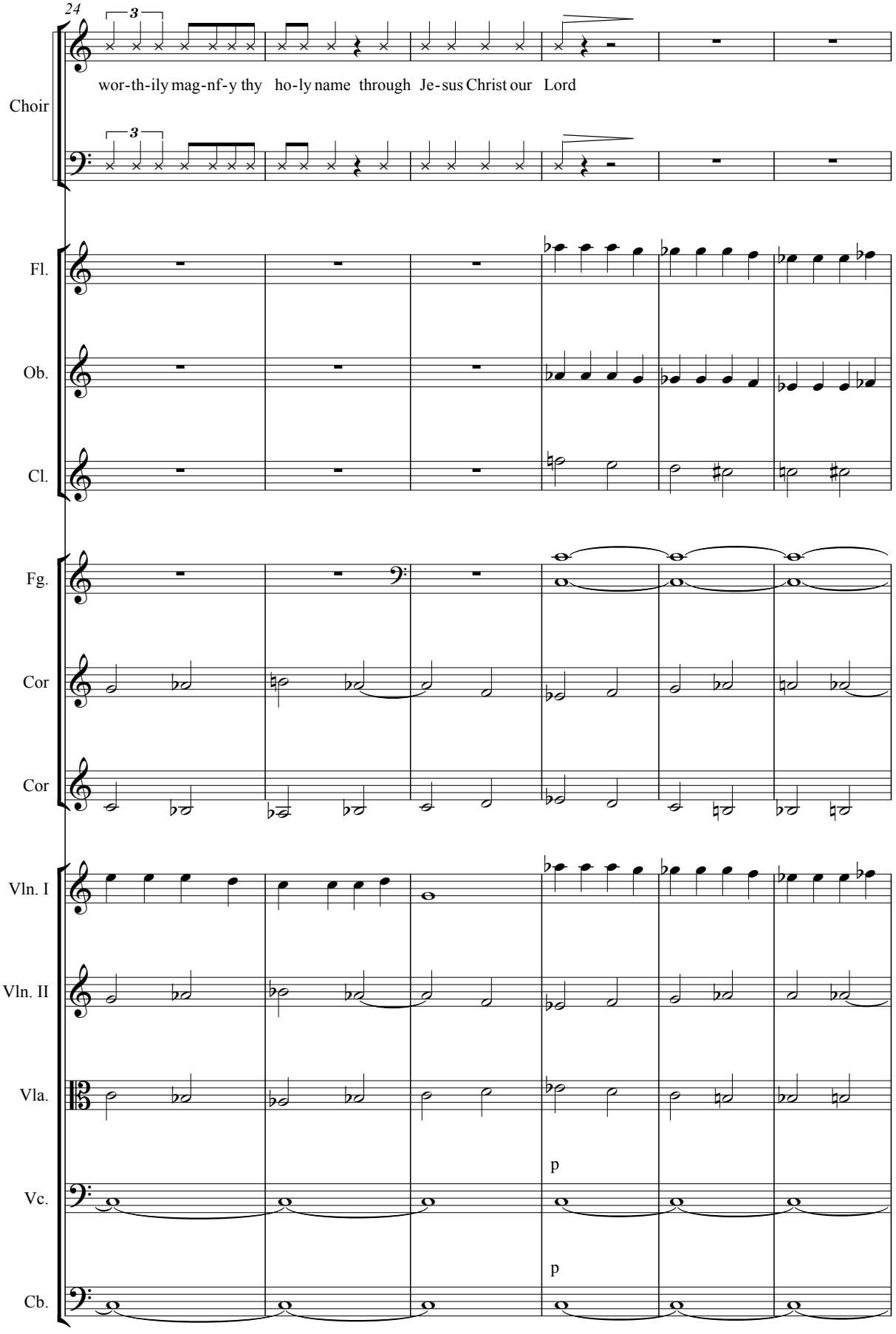
Gregory Clifton-Smith

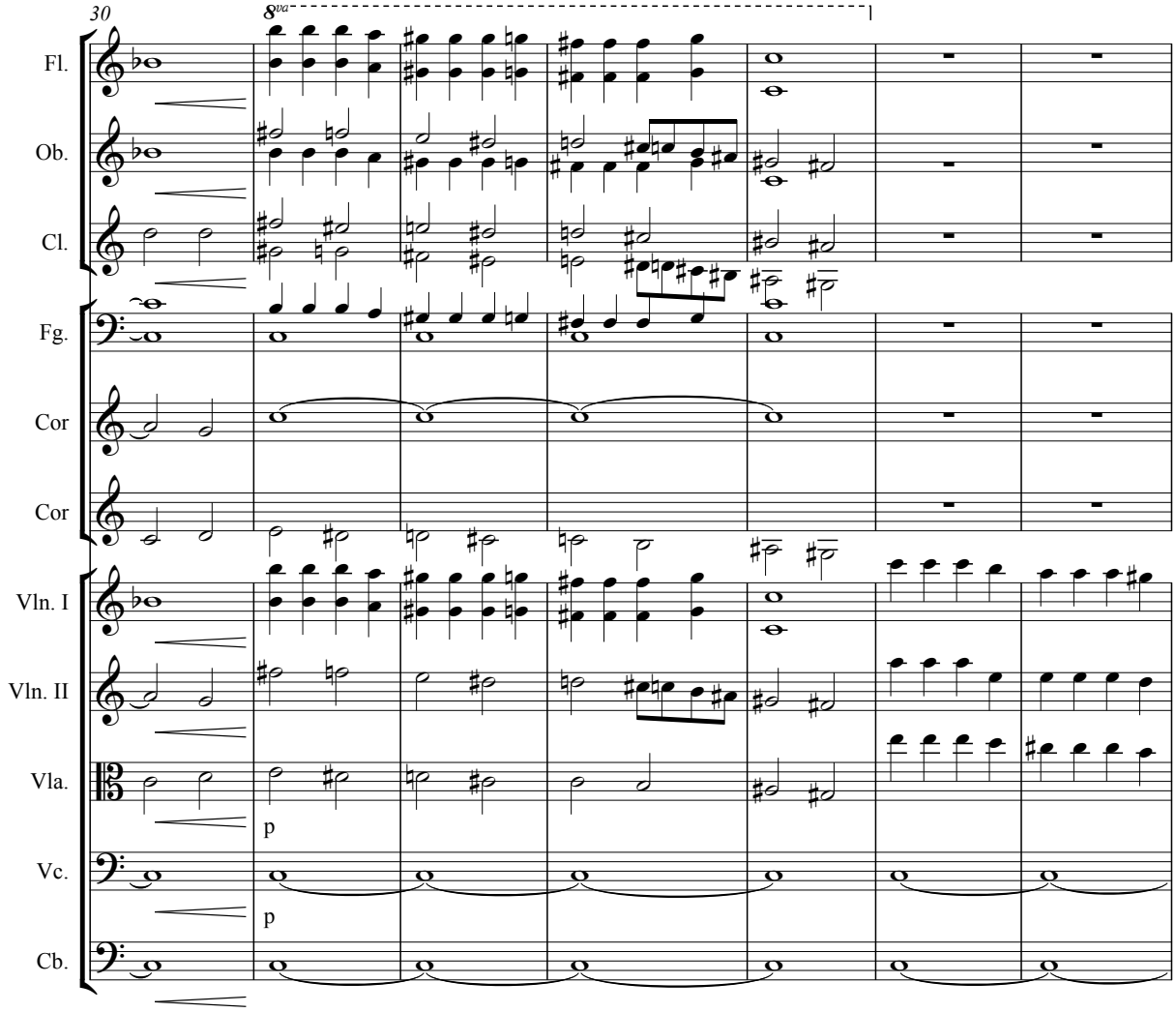
Collage

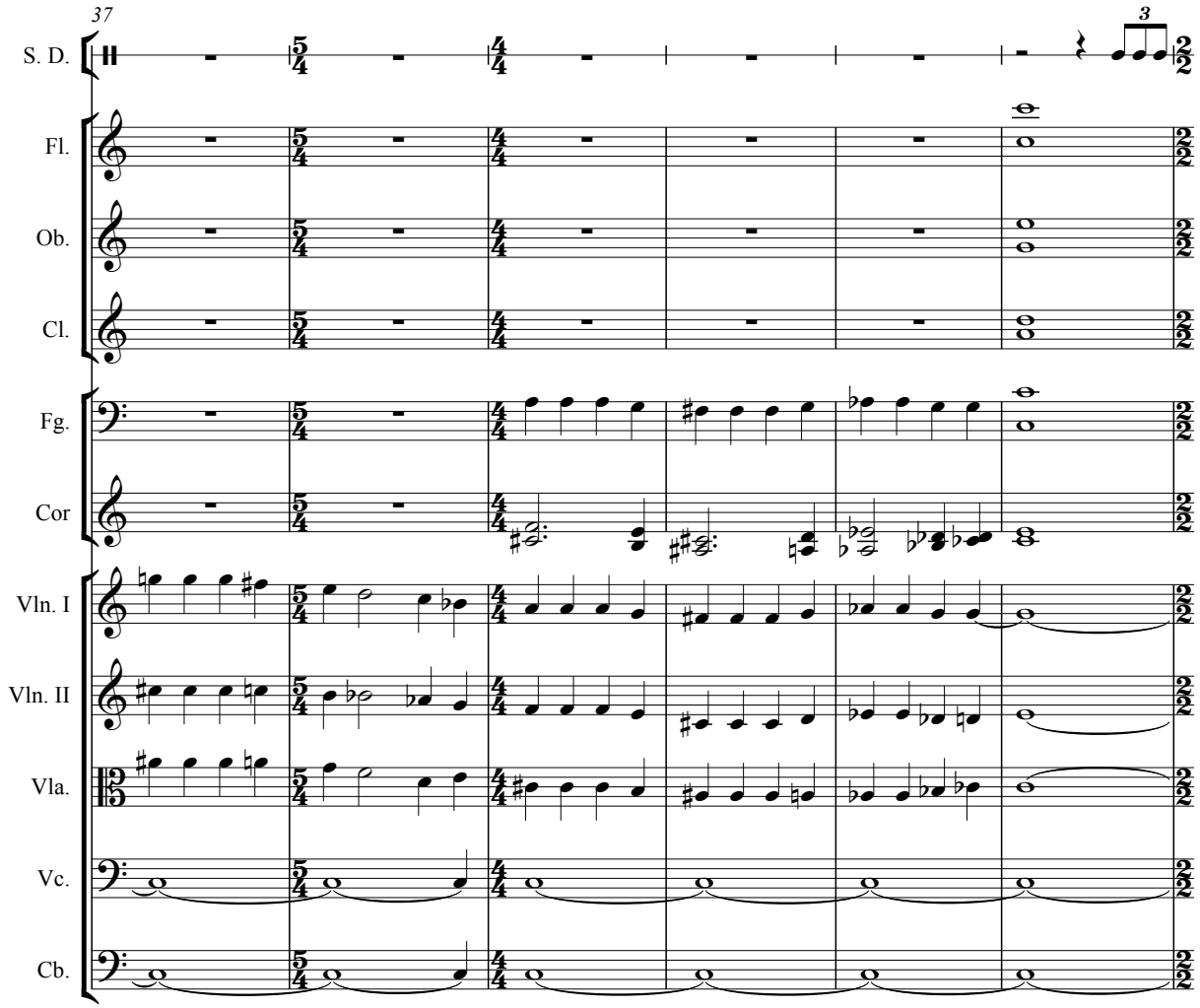
Prima Pars

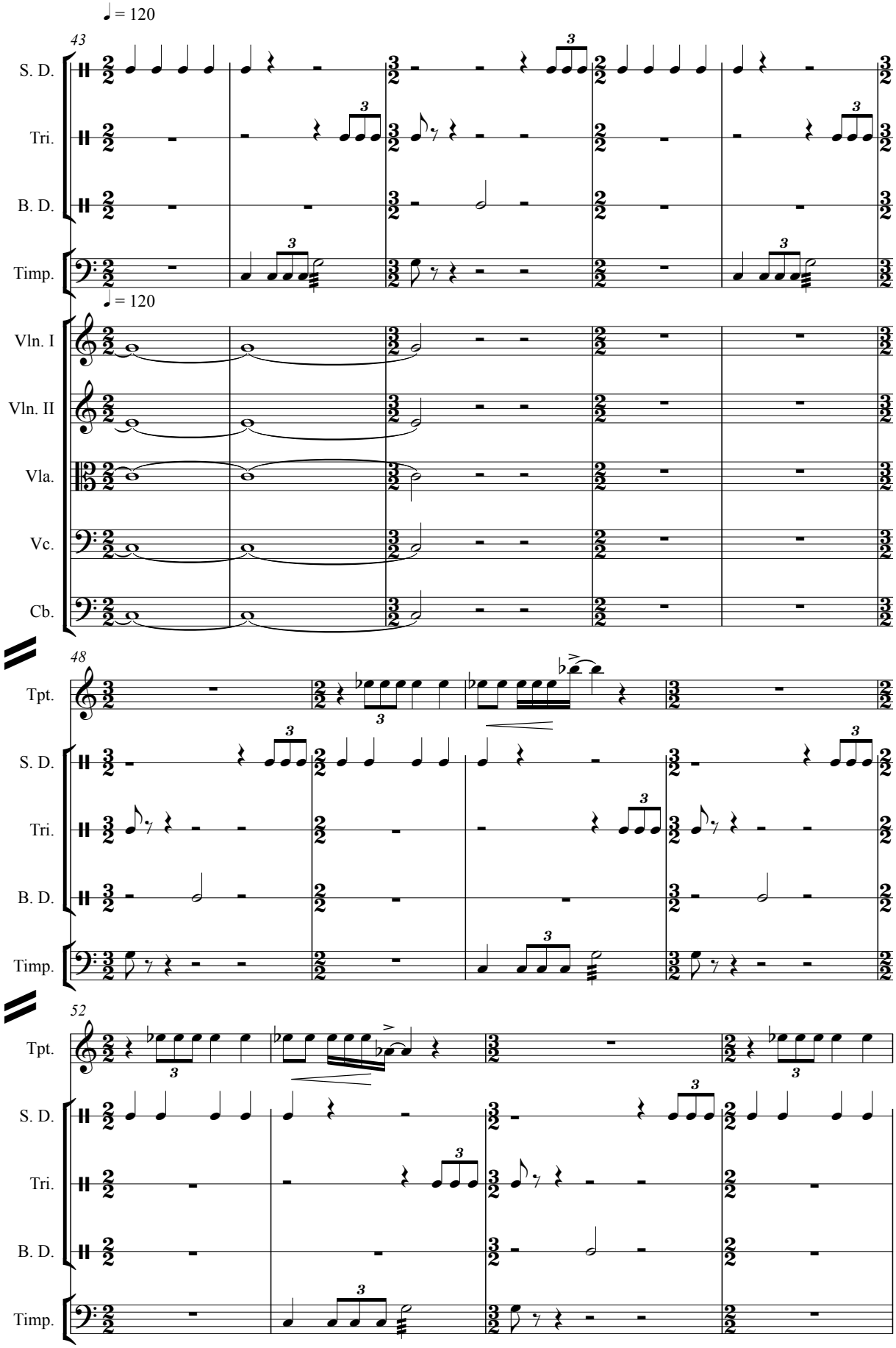
Gregory Clifton -Smith

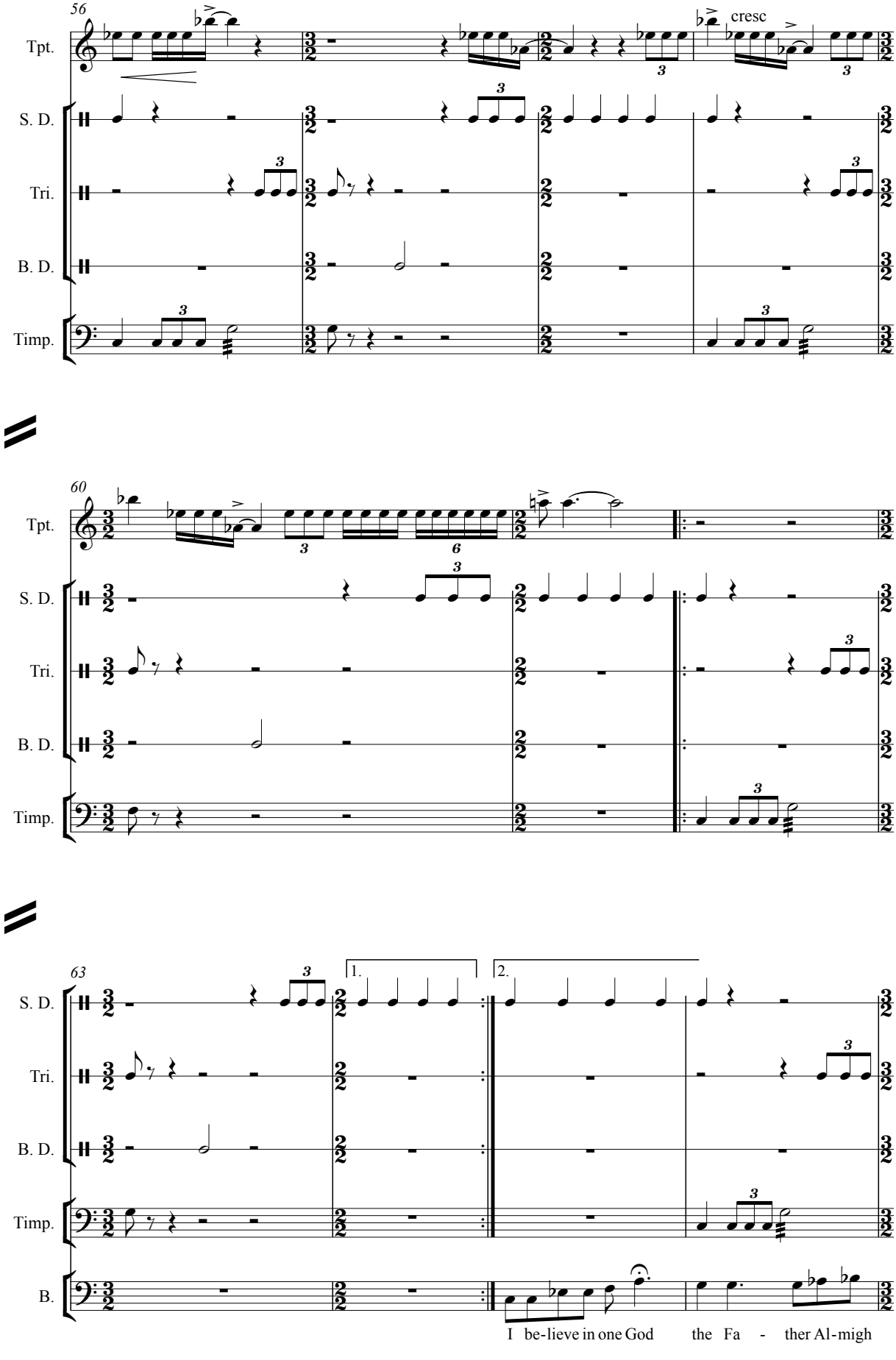


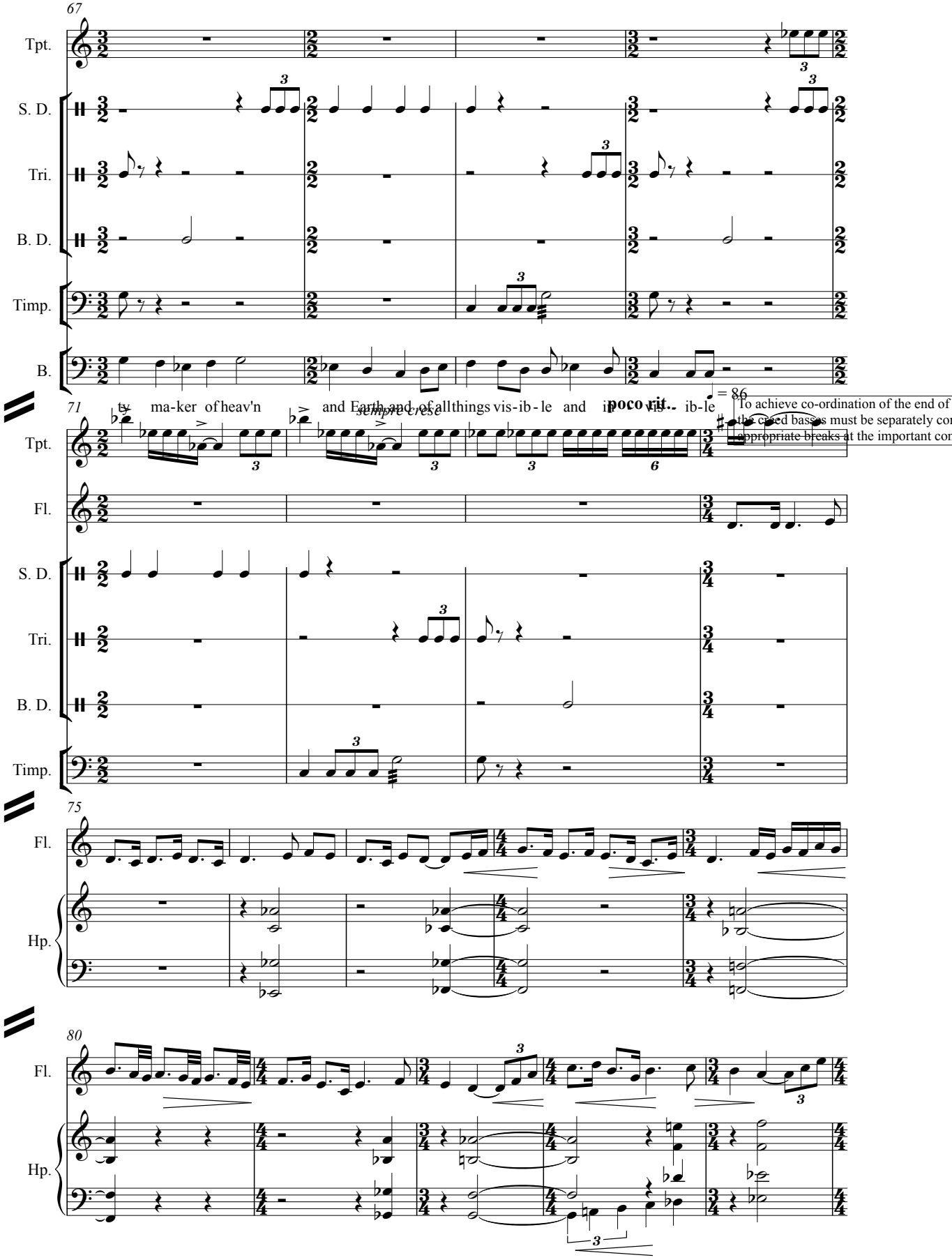

24
3
wor-th-ily mag-nf-y thy ho-ly name through Je-sus Christ our Lord
Choir
Fl.
Ob.
Cl.
Fg.
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.
p
p

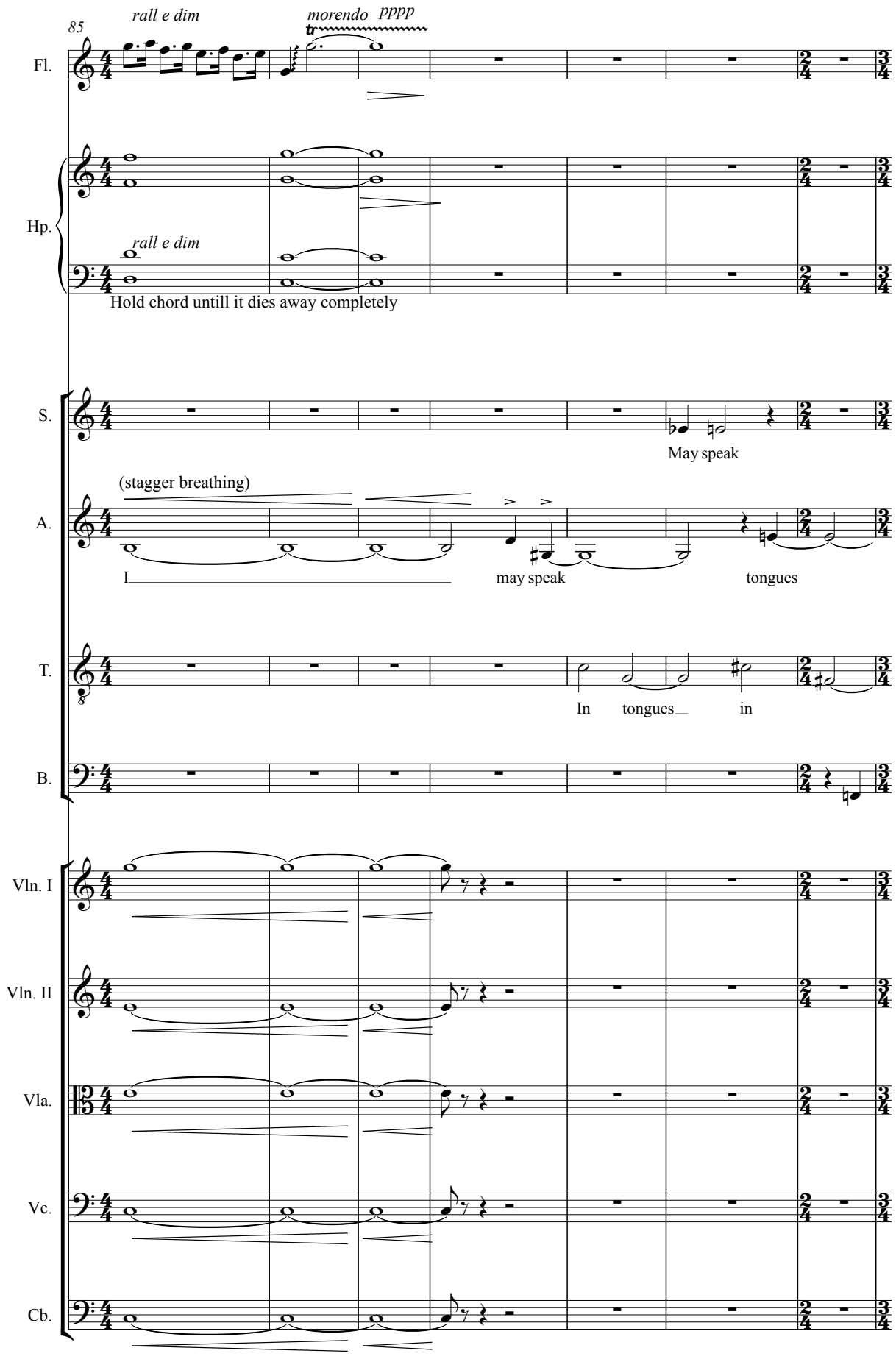

30
8va
Fl.
Ob.
Cl.
Fg.
Cor
Cor
Vln. I
Vln. II
Vla.
p
Vc.
p
Cb.

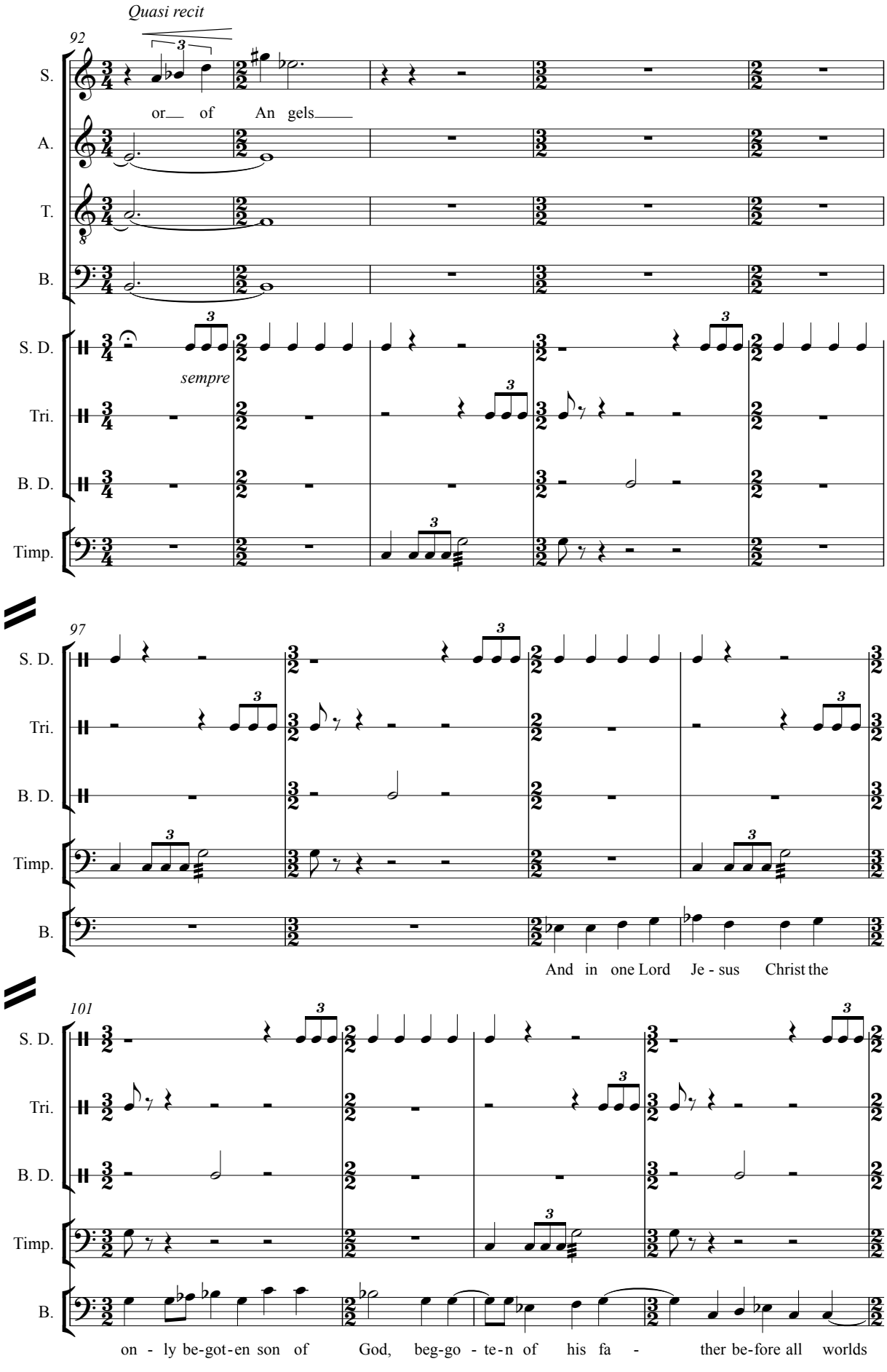

37
3
S. D.
Fl.
Ob.
Cl.
Fg.
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.

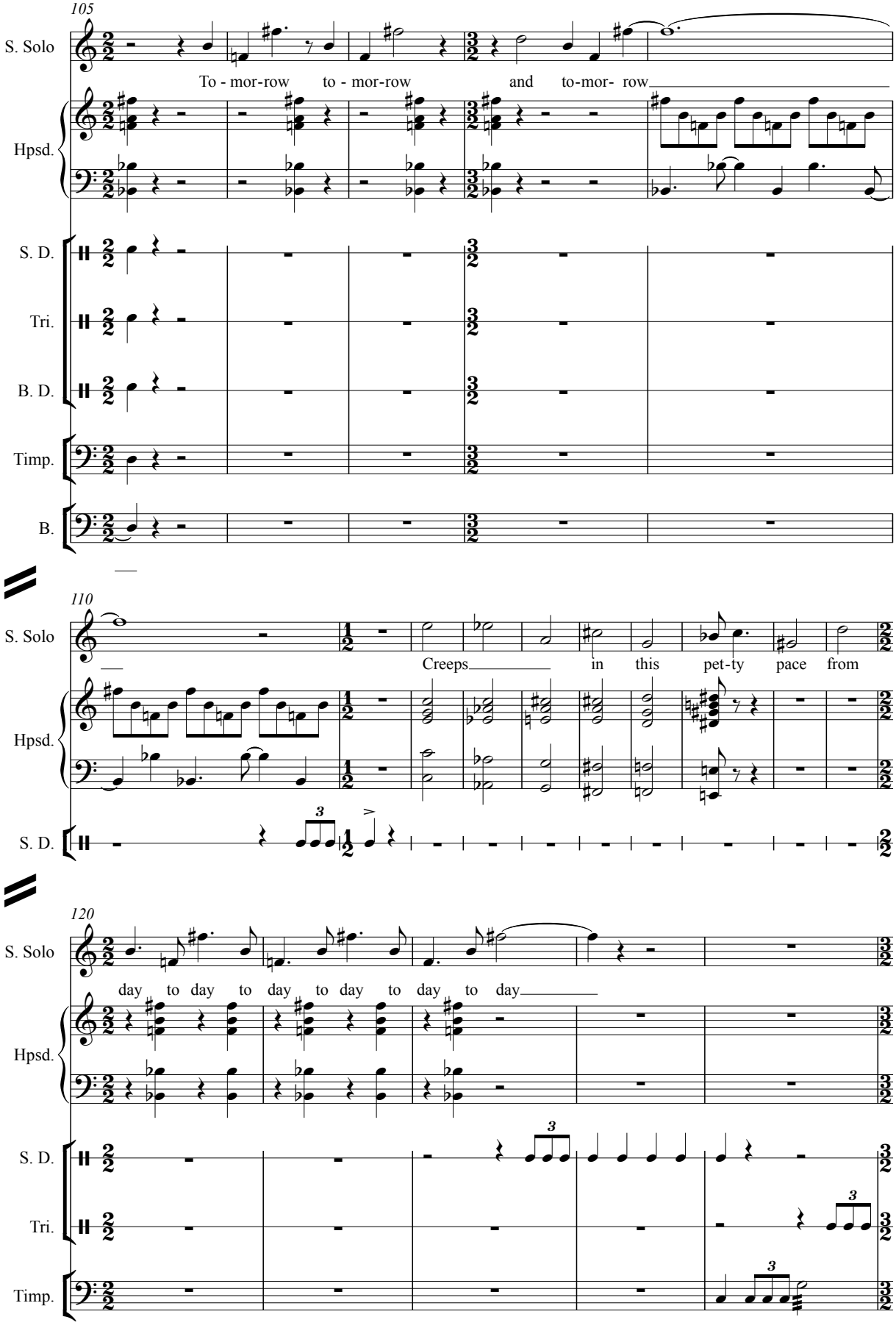

♩ = 120
43
S. D.
Tri.
B. D.
Timp.
♩ = 120
Vln. I
Vln. II
Vla.
Vc.
Cb.
48
Tpt.
S. D.
Tri.
B. D.
Timp.
52
Tpt.
S. D.
Tri.
B. D.
Timp.

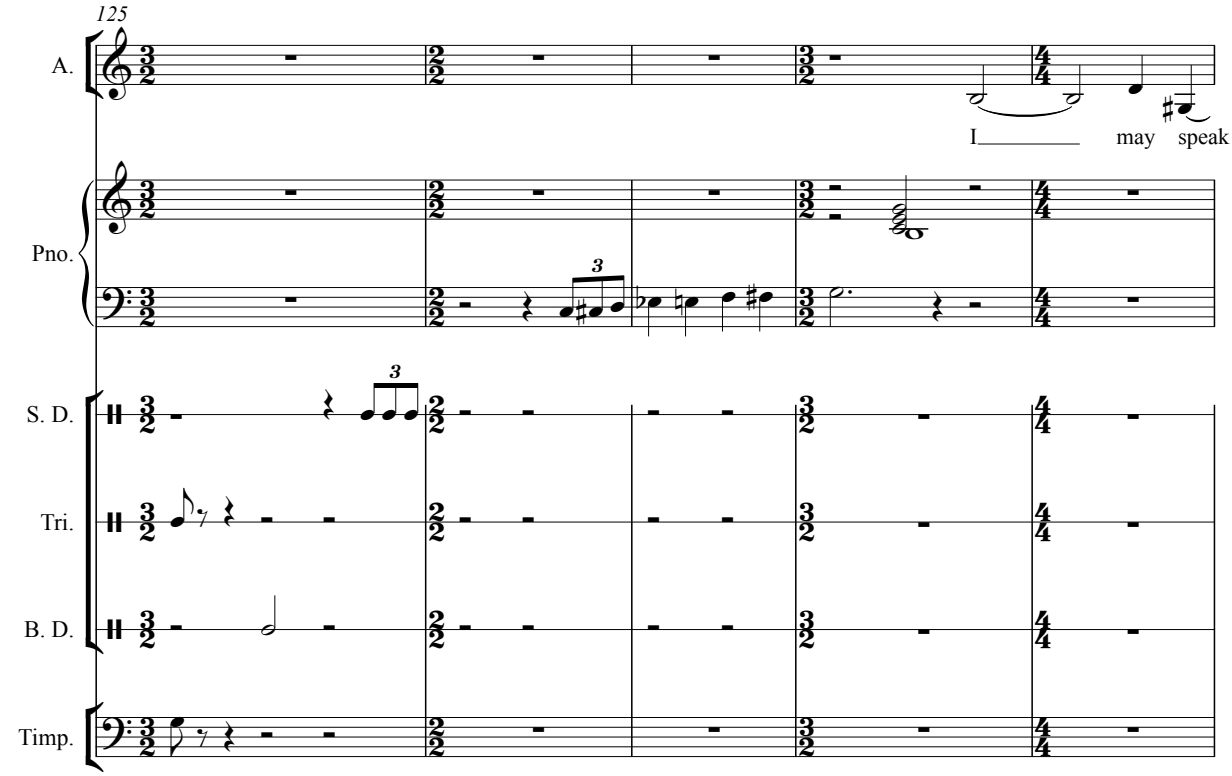

56
Tpt.
S. D.
Tri.
B. D.
Timp.
cresc
60
63
1.
2.
B.
I be-lieve in one God the Fa - ther Al-migh

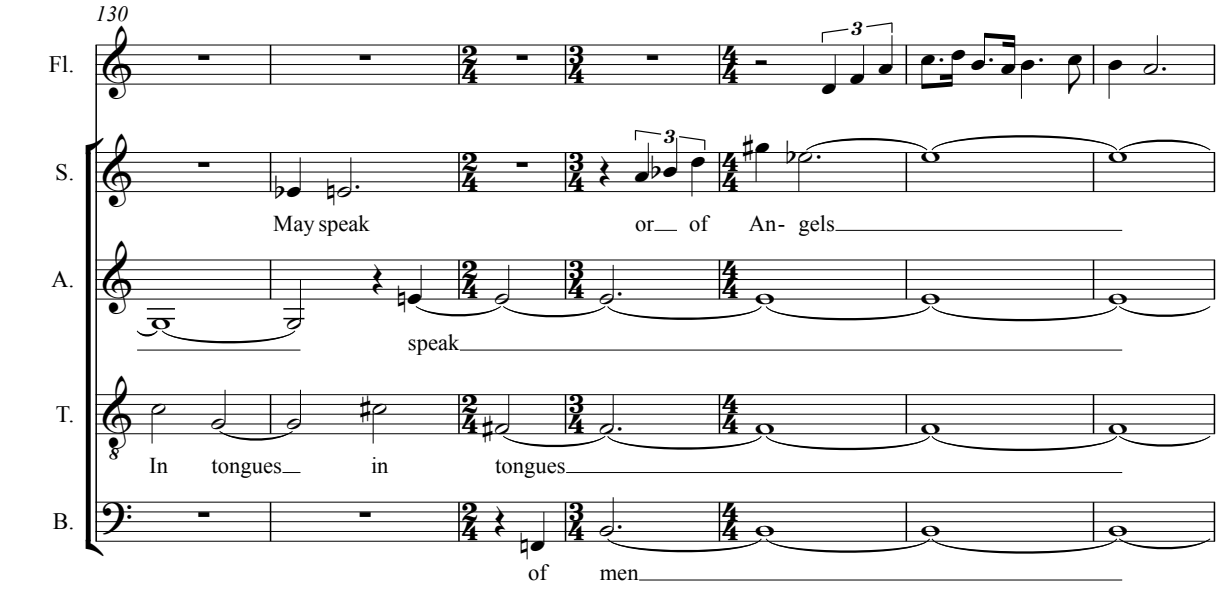

67
Tpt.
S. D.
Tri.
B. D.
Timp.
B.
71
ty ma-ker of heav'n and Earth and of all things vis-ib-le and in vis-ib-le
sempre cresc
poco rit.
♩ = 86
To achieve co-ordination of the end of
the caged basses must be separately con
appropriate breaks at the important con
Tpt.
Fl.
S. D.
Tri.
B. D.
Timp.
75
Fl.
Hp.
80
Fl.
Hp.

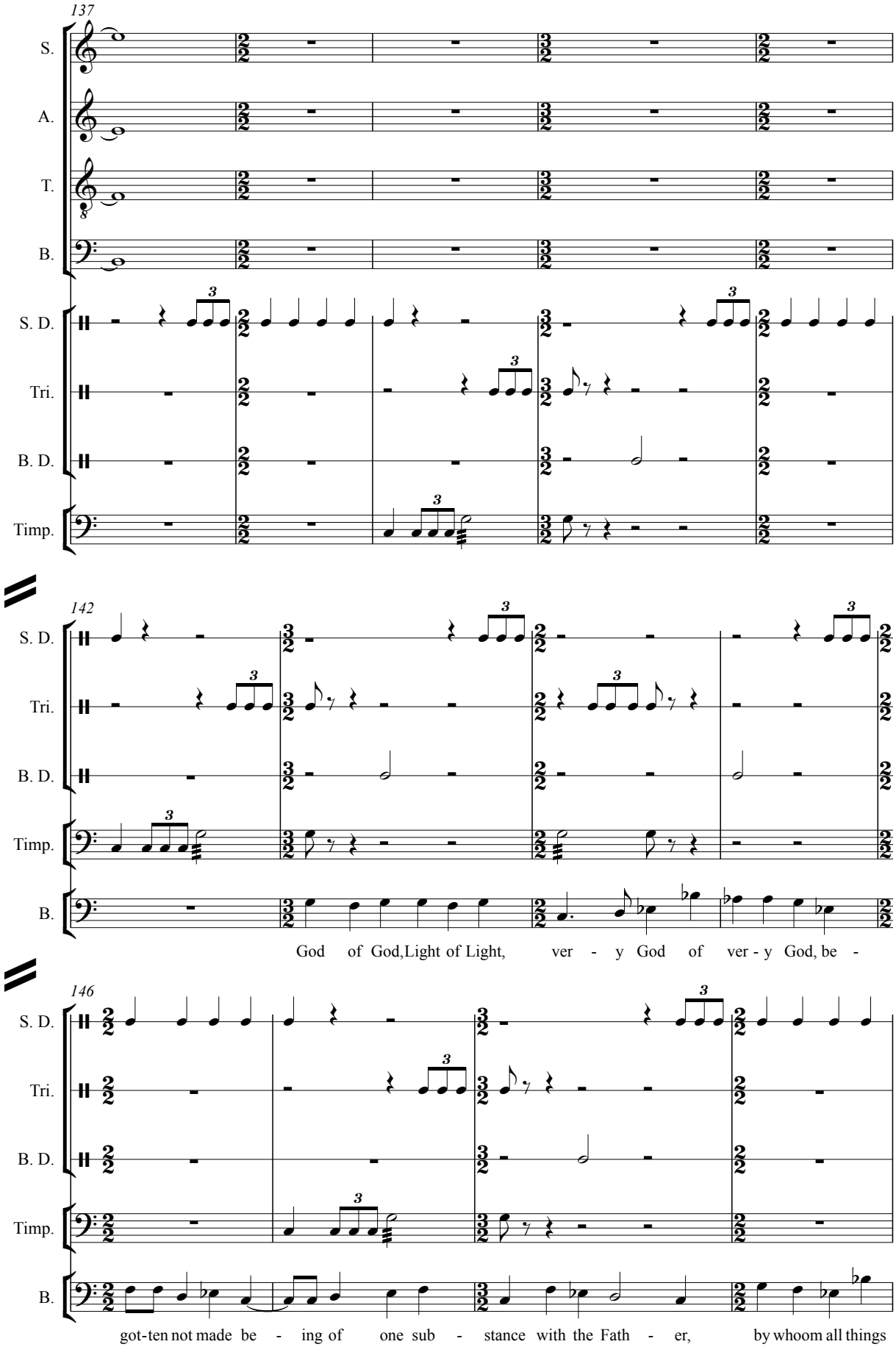

85
rall e dim
morendo pppp
tr
Fl.
Hp.
rall e dim
Hold chord untill it dies away completely
S.
May speak
(stagger breathing)
A.
I
may speak
tongues
T.
In tongues in
B.
Vln. I
Vln. II
Vla.
Vc.
Cb.

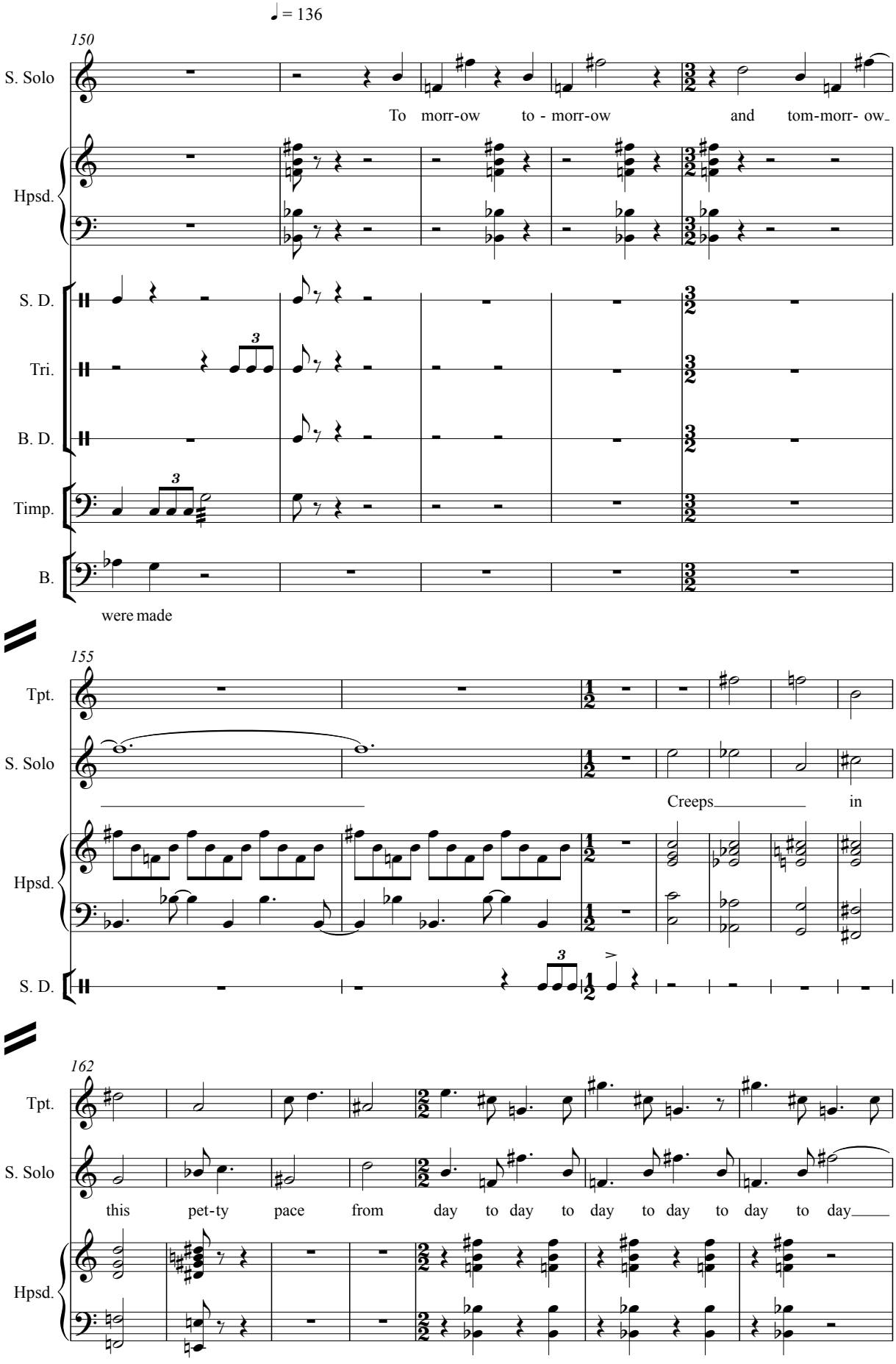

Quasi recit
92
S.
A.
T.
B.
S. D.
Tri.
B. D.
Timp.
or of An gels
sempre
97
And in one Lord Je - sus Christ the
101
on - ly be-got-en son of God, beg-go - te-n of his fa - ther be-fore all worlds

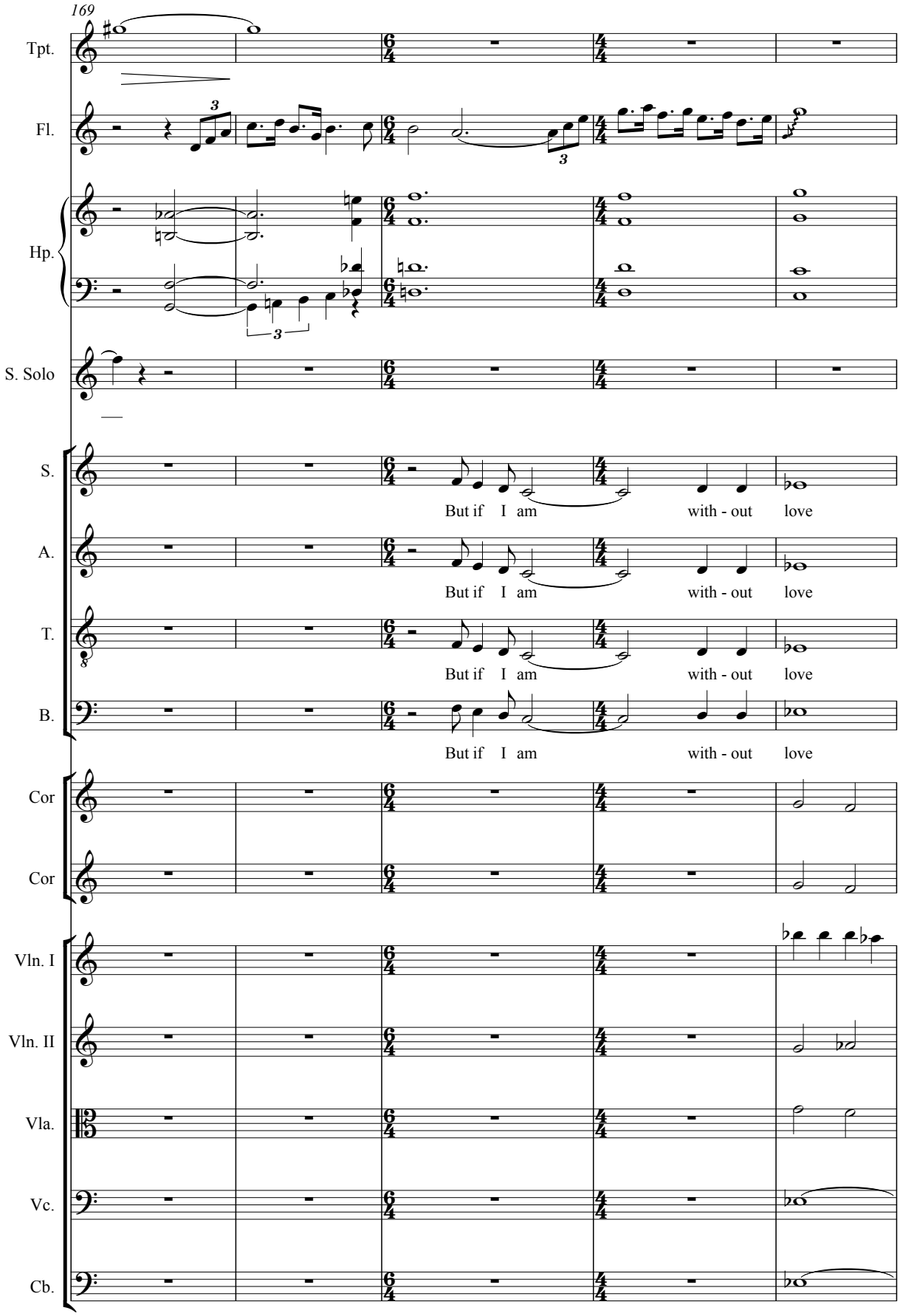

105
S. Solo
To - mor-row to - mor-row and to-mor- row
Hpsd.
S. D.
Tri.
B. D.
Timp.
B.
110
S. Solo
Creeps in this pet-ty pace from
Hpsd.
S. D.
120
S. Solo
day to day to day to day to day to day
Hpsd.
S. D.
Tri.
Timp.

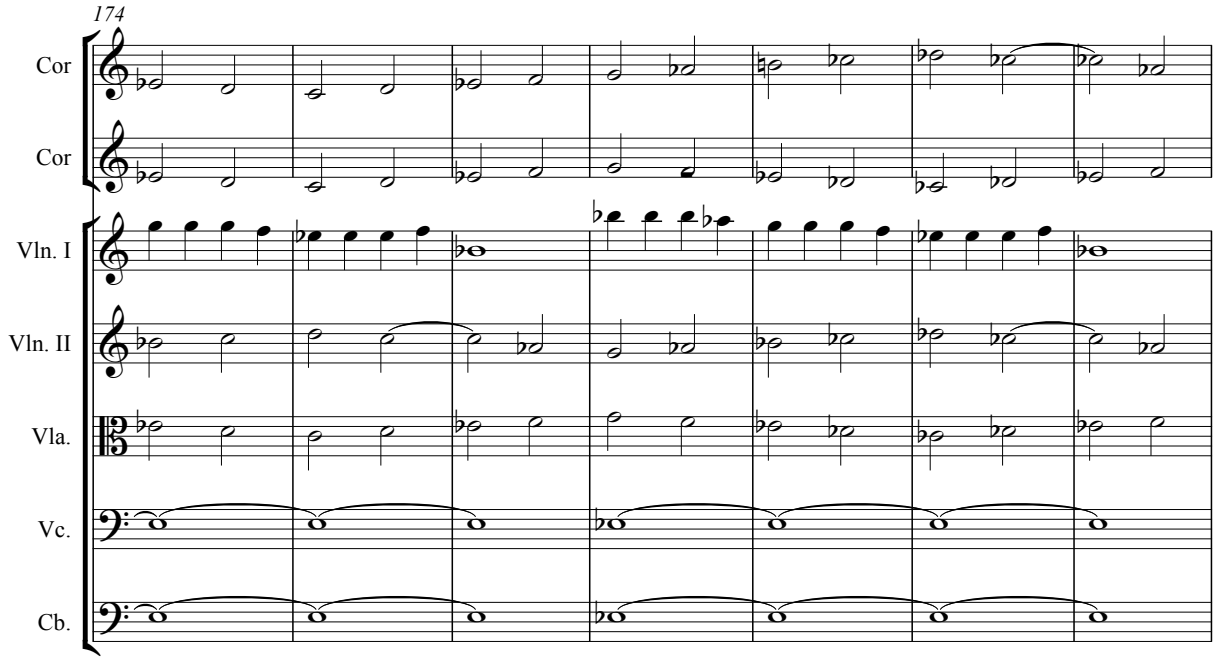

125
A.
I may speak
Pno.
S. D.
Tri.
B. D.
Timp.

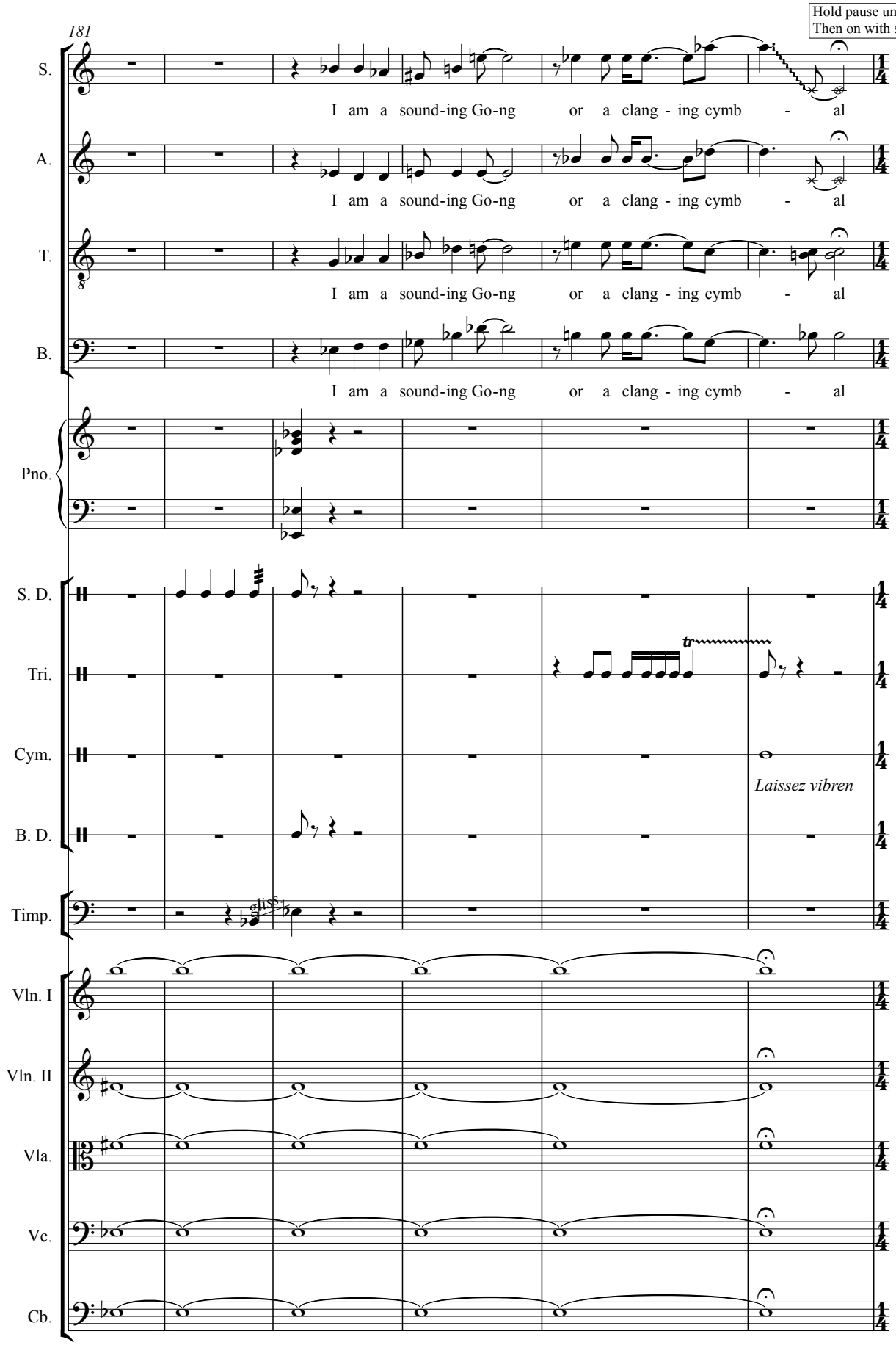

130
Fl.
S.
May speak or of An- gels
A.
speak
T.
In tongues in tongues
B.
of men

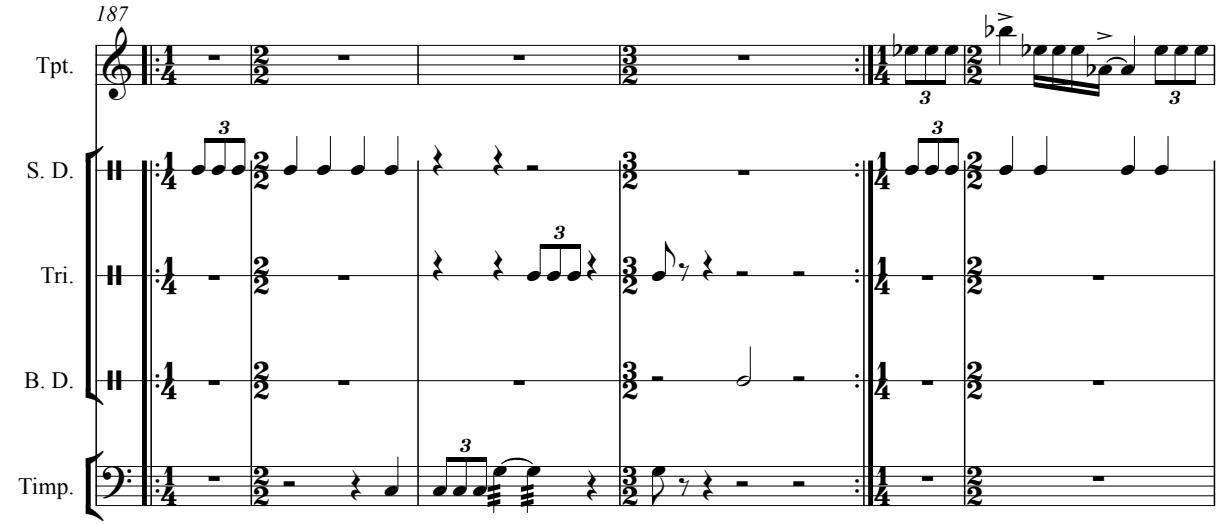

137
S.
A.
T.
B.
S. D.
Tri.
B. D.
Timp.
142
S. D.
Tri.
B. D.
Timp.
B.
God of God,Light of Light, ver - y God of ver - y God, be -
146
S. D.
Tri.
B. D.
Timp.
B.
got-ten not made be - ing of one sub - stance with the Fath - er, by whoom all things

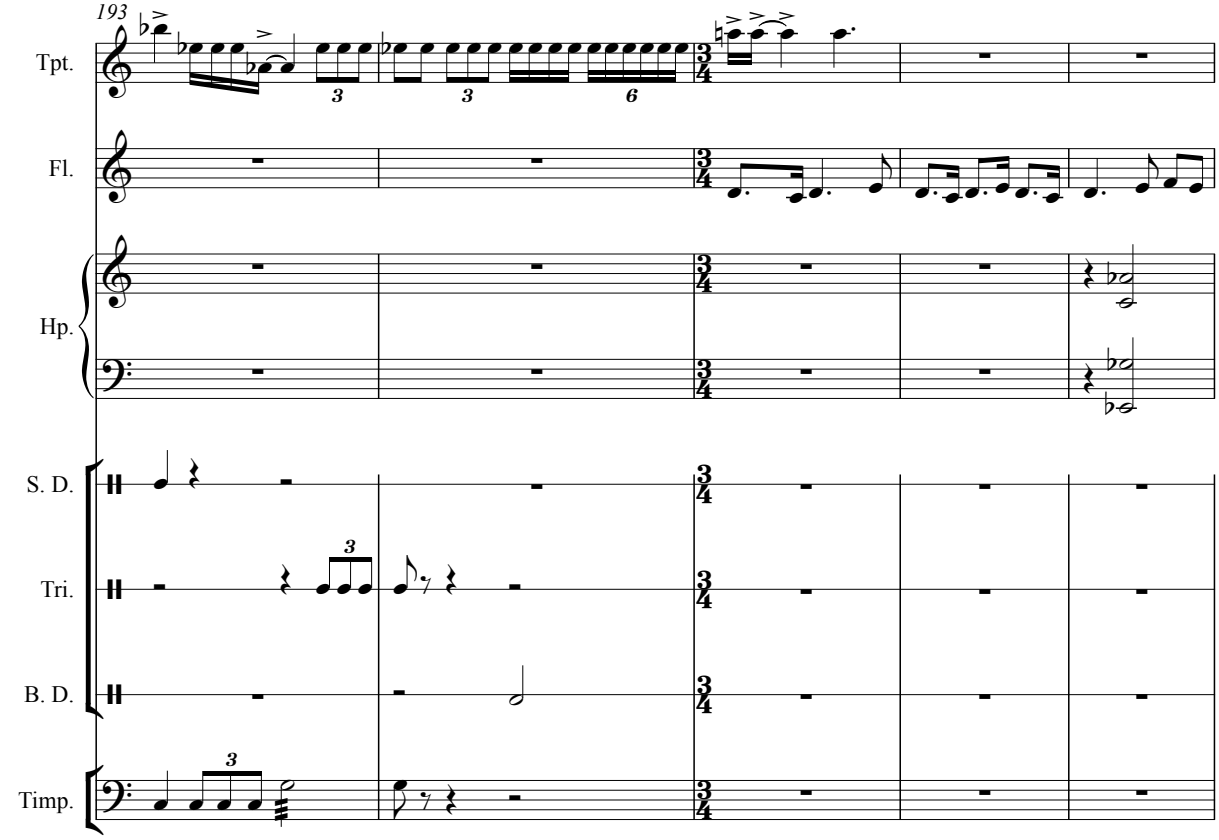

♩ = 136
150
S. Solo
To morr-ow to - morr-ow and tom-morr- ow
Hpsd.
S. D.
Tri.
B. D.
Timp.
B.
were made
155
Tpt.
S. Solo
Creeps in
Hpsd.
S. D.
162
Tpt.
S. Solo
this pet-ty pace from day to day to day to day to day to day
Hpsd.

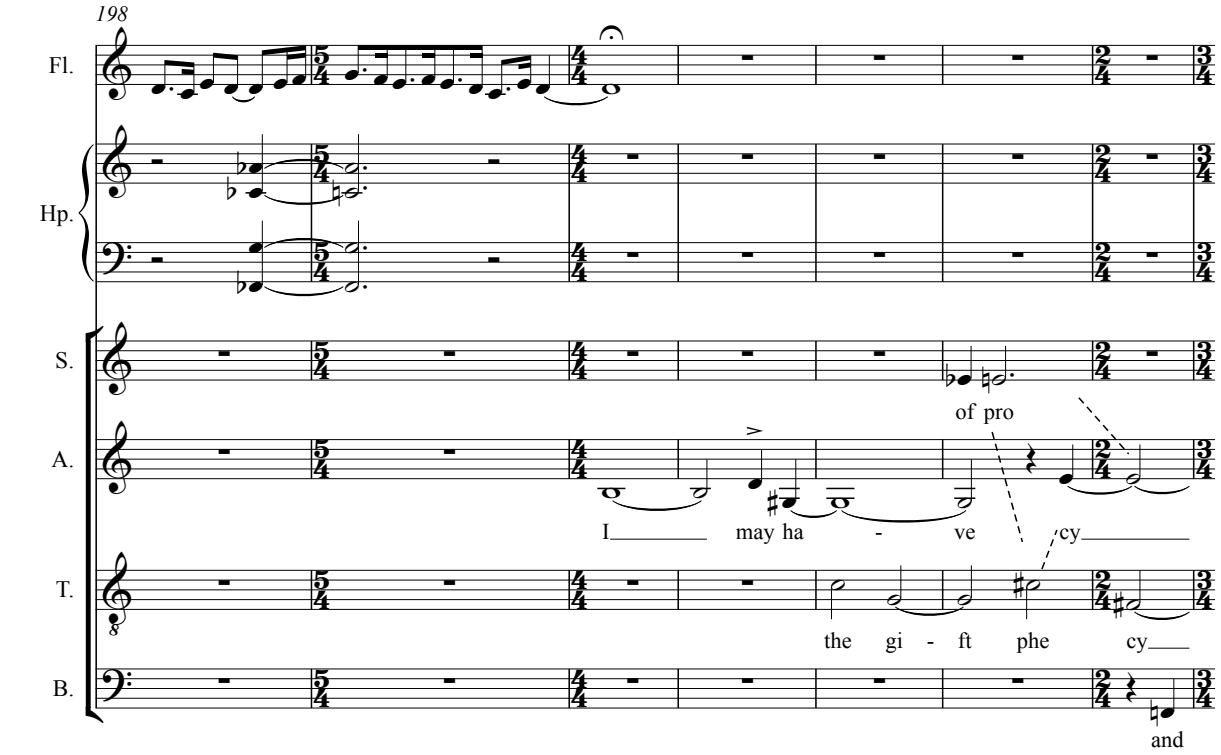

169
Tpt.
Fl.
Hp.
S. Solo
S.
But if I am with - out love
A.
But if I am with - out love
T.
But if I am with - out love
B.
But if I am with - out love
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.

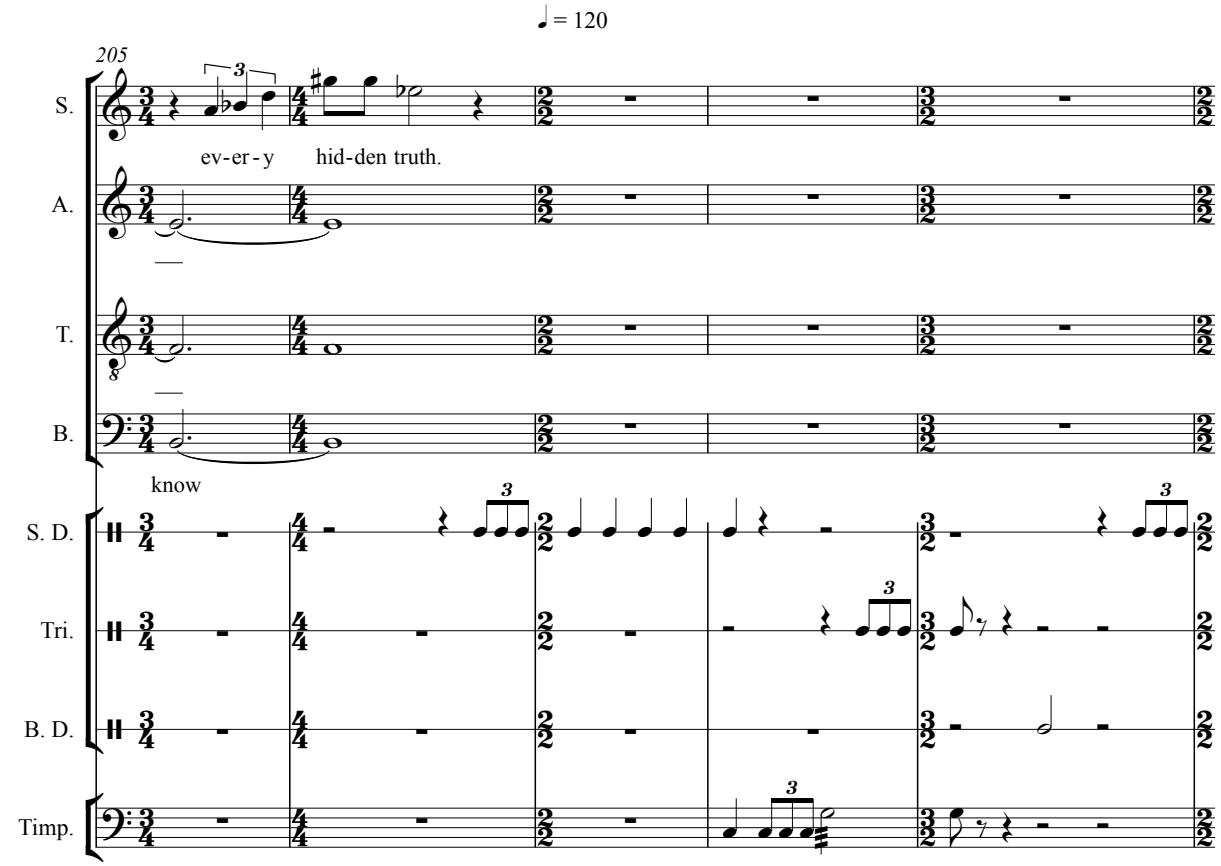

174
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.

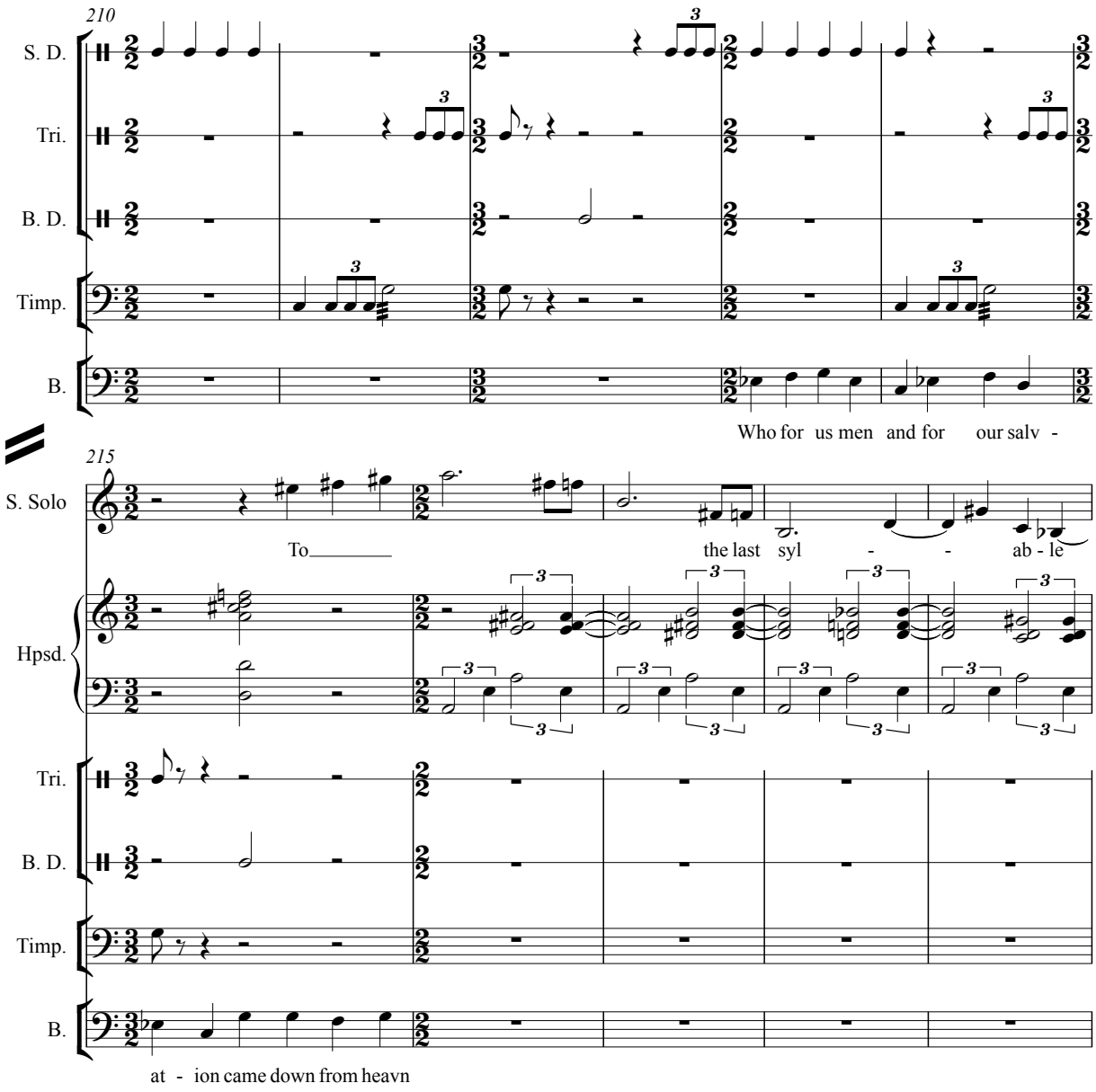

181
Hold pause until cymbol has die
Then on with side drum.
S.
A.
T.
B.
I am a sound-ing Go-ng or a clang - ing cymb - al
Pno.
S. D.
Tri.
Cym.
Laissez vibren
B. D.
Timp.
gliss.
Vln. I
Vln. II
Vla.
Vc.
Cb.

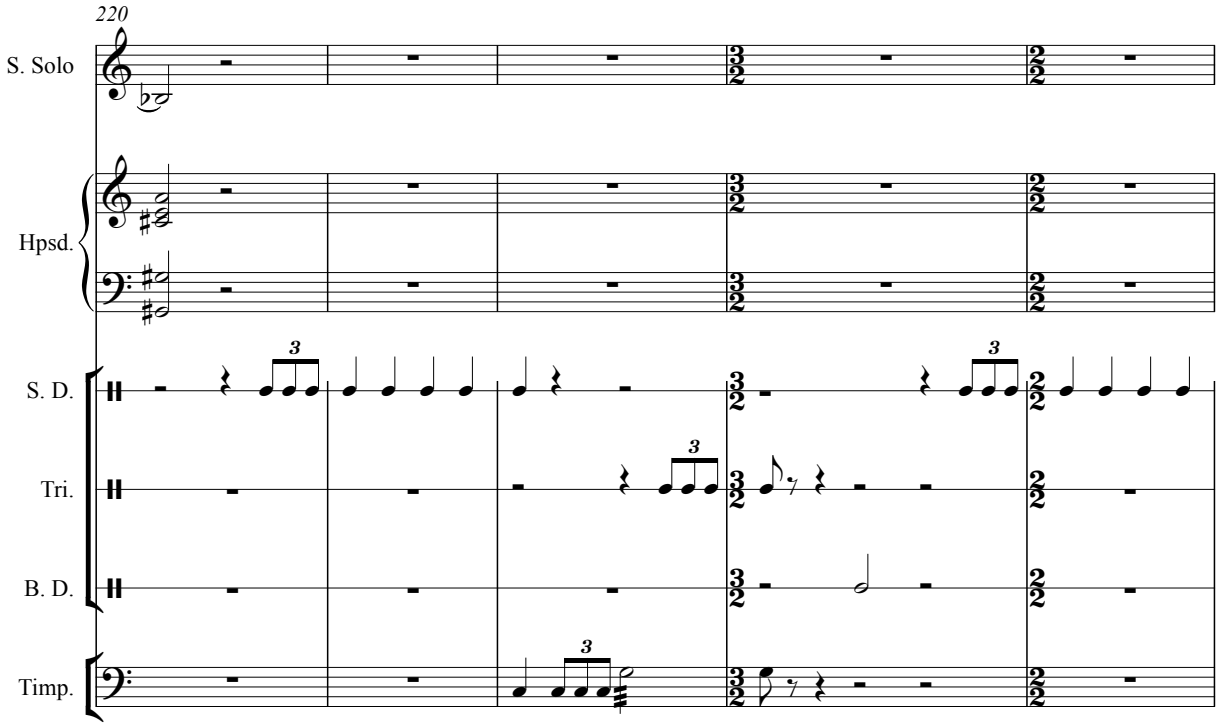

187
Tpt.
S. D.
Tri.
B. D.
Timp.

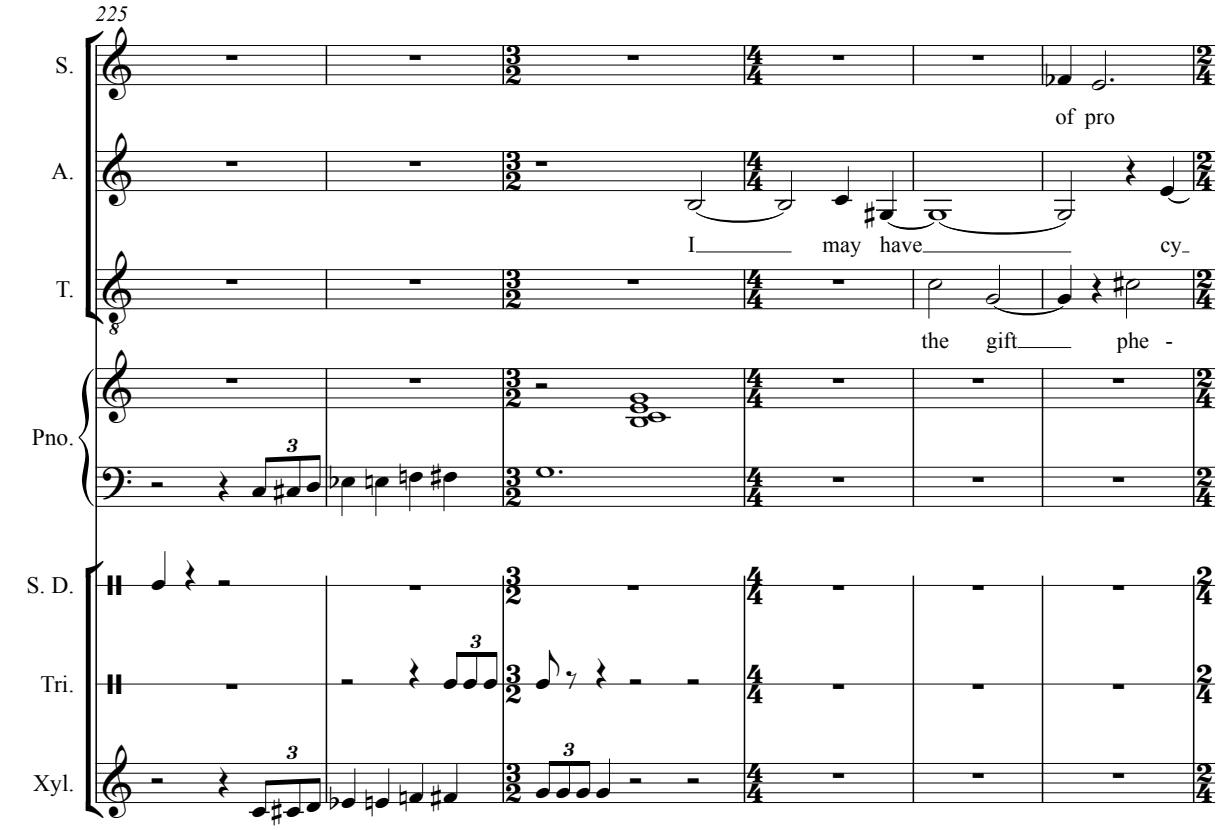

193
Tpt.
Fl.
Hp.
S. D.
Tri.
B. D.
Timp.

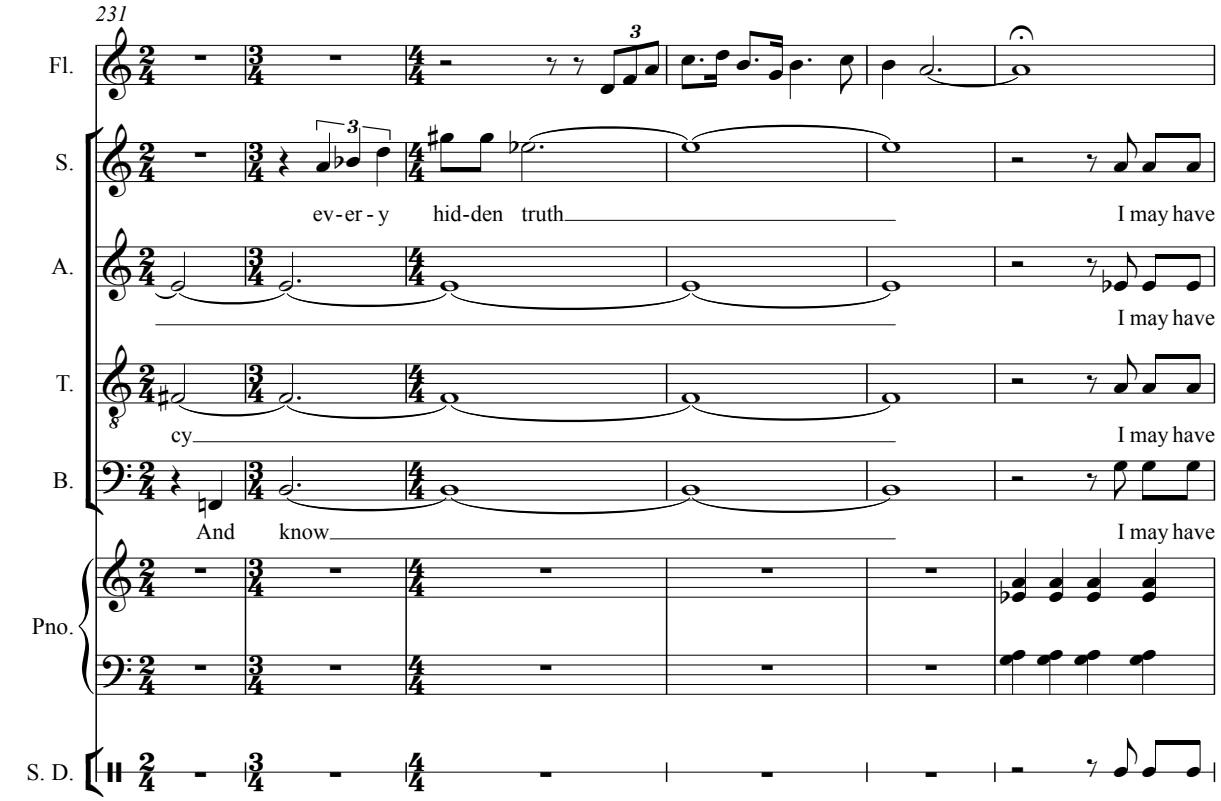

198
Fl.
Hp.
S.
A.
T.
B.
of pro
I may ha - ve cy
the gi - ft phe cy
and

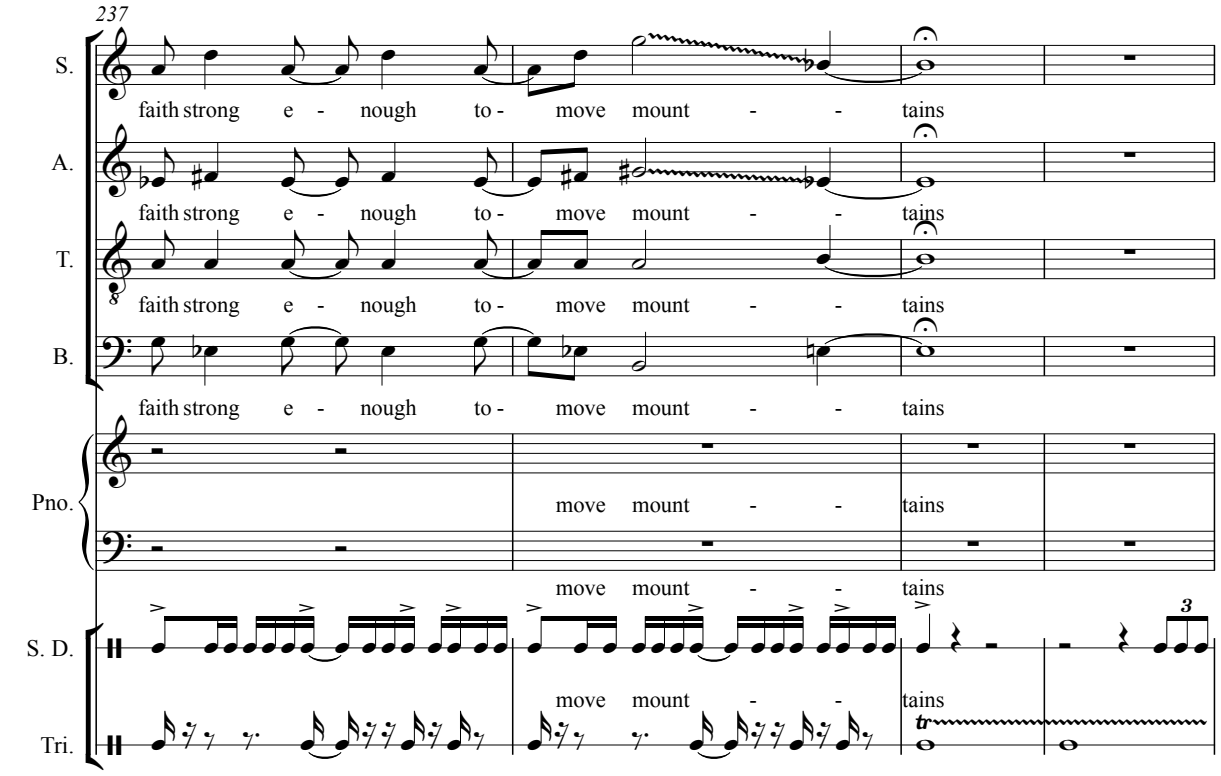

♩ = 120
205
S.
A.
T.
B.
S. D.
Tri.
B. D.
Timp.
ev-er-y hid-den truth.
know

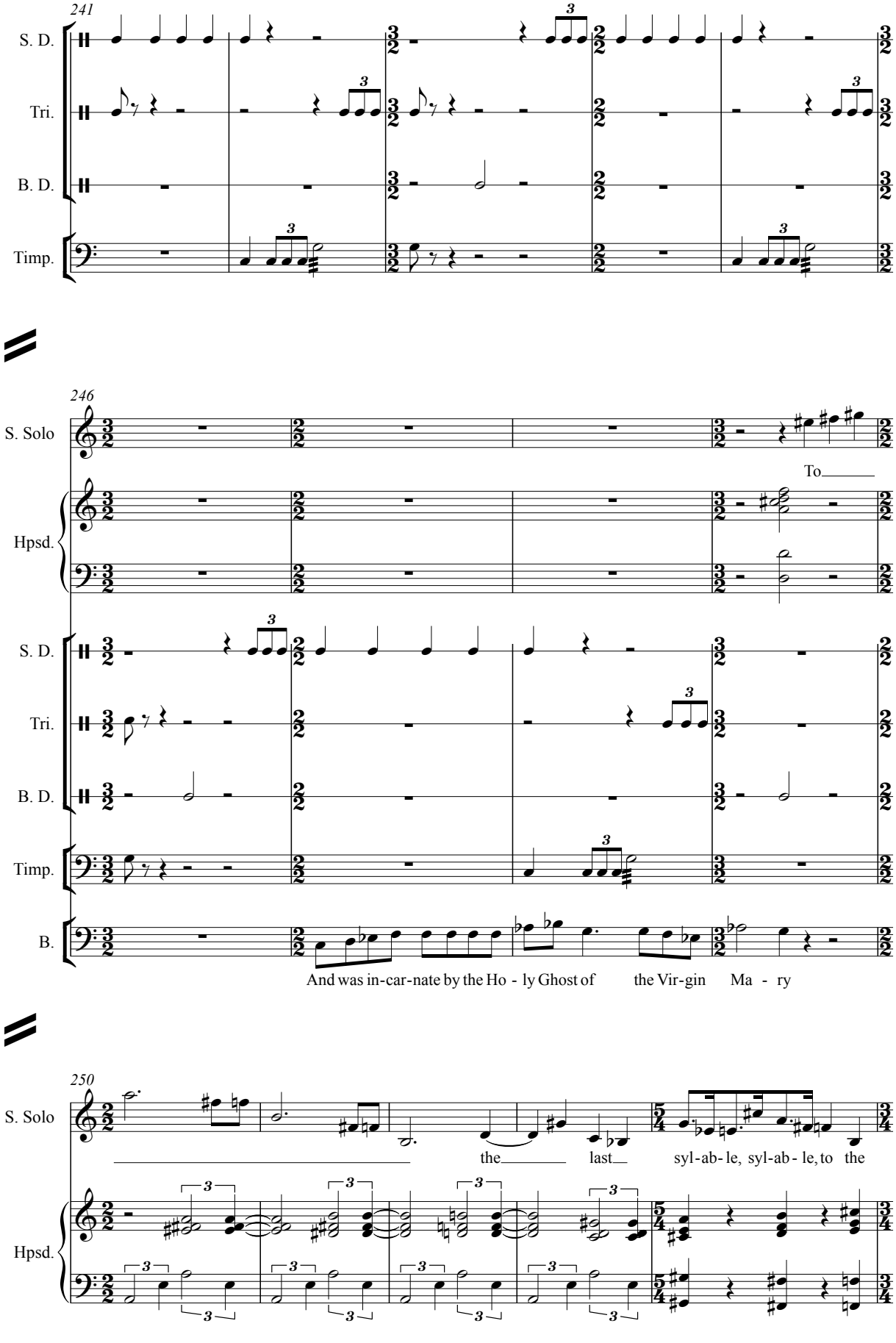

210
S. D.
Tri.
B. D.
Timp.
B.
Who for us men and for our salv -
215
S. Solo
To
the last syl - - ab - le
Hpsd.
Tri.
B. D.
Timp.
B.
at - ion came down from heavn

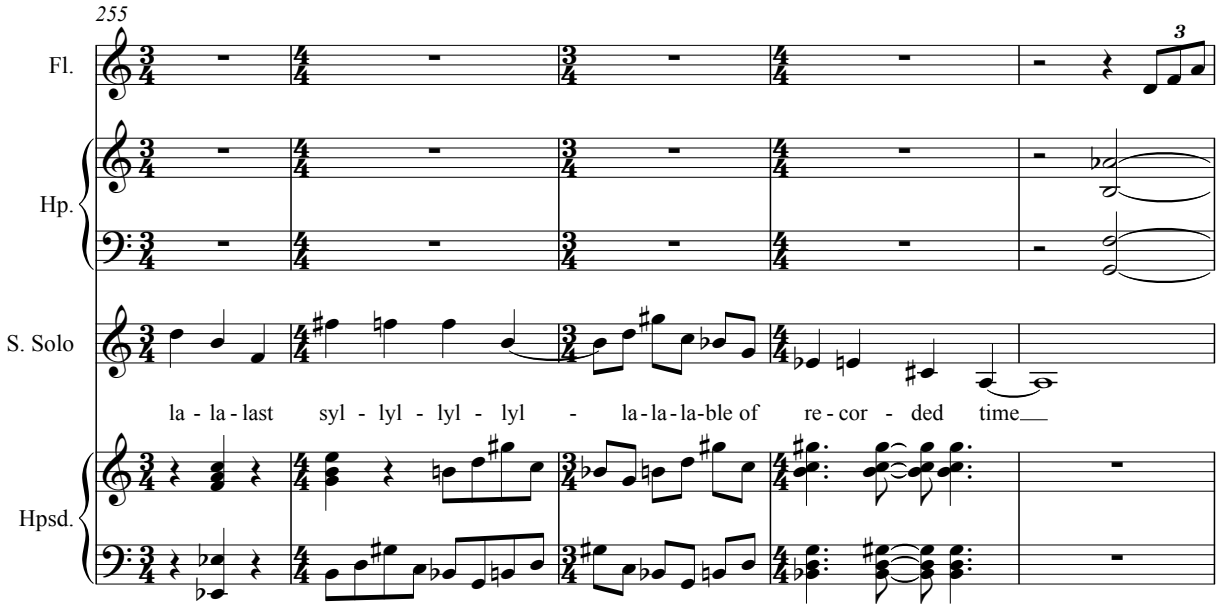

220
S. Solo
Hpsd.
S. D.
Tri.
B. D.
Timp.

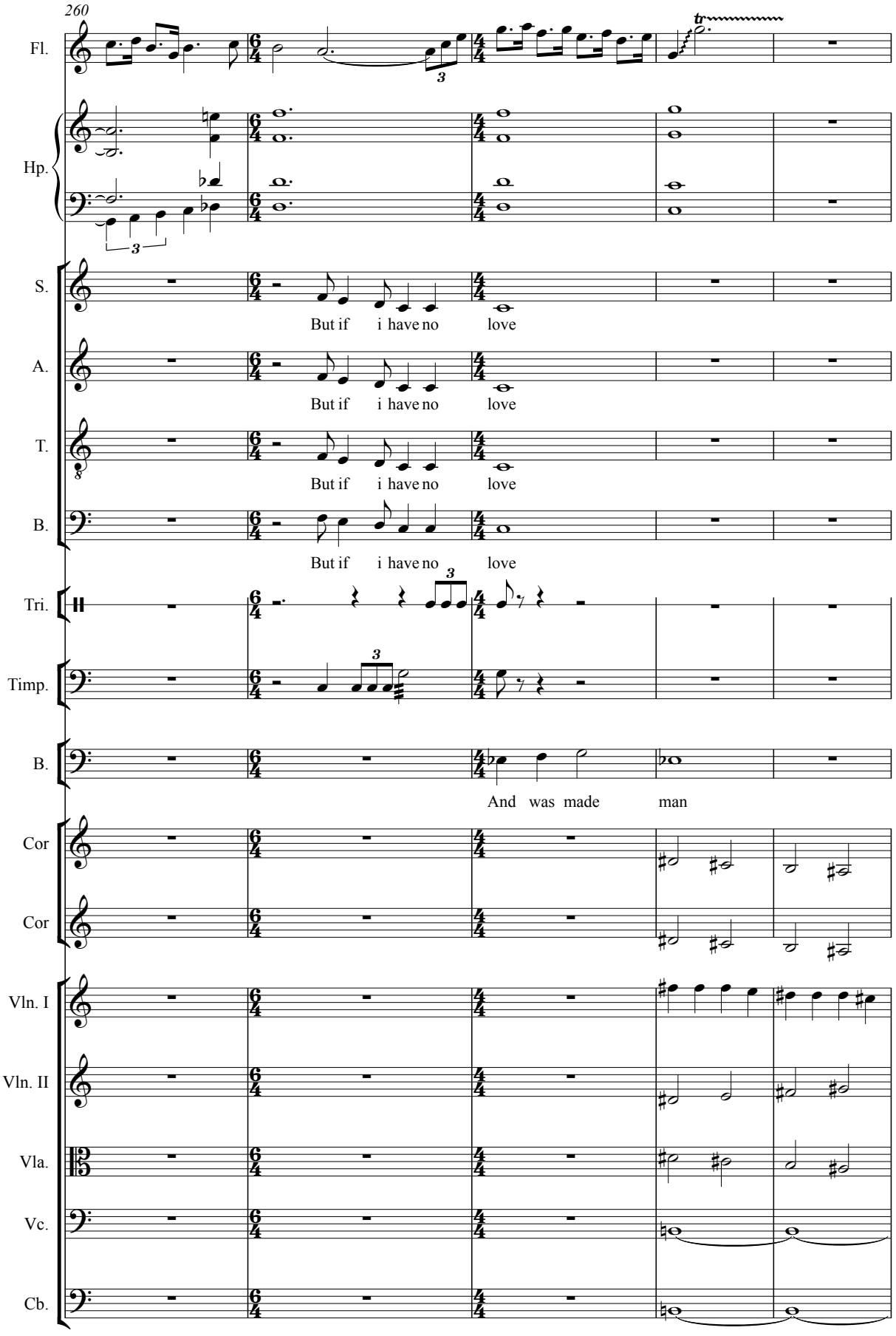

225
S.
A.
T.
Pno.
S. D.
Tri.
Xyl.
of pro
I may have cy-
the gift phe -

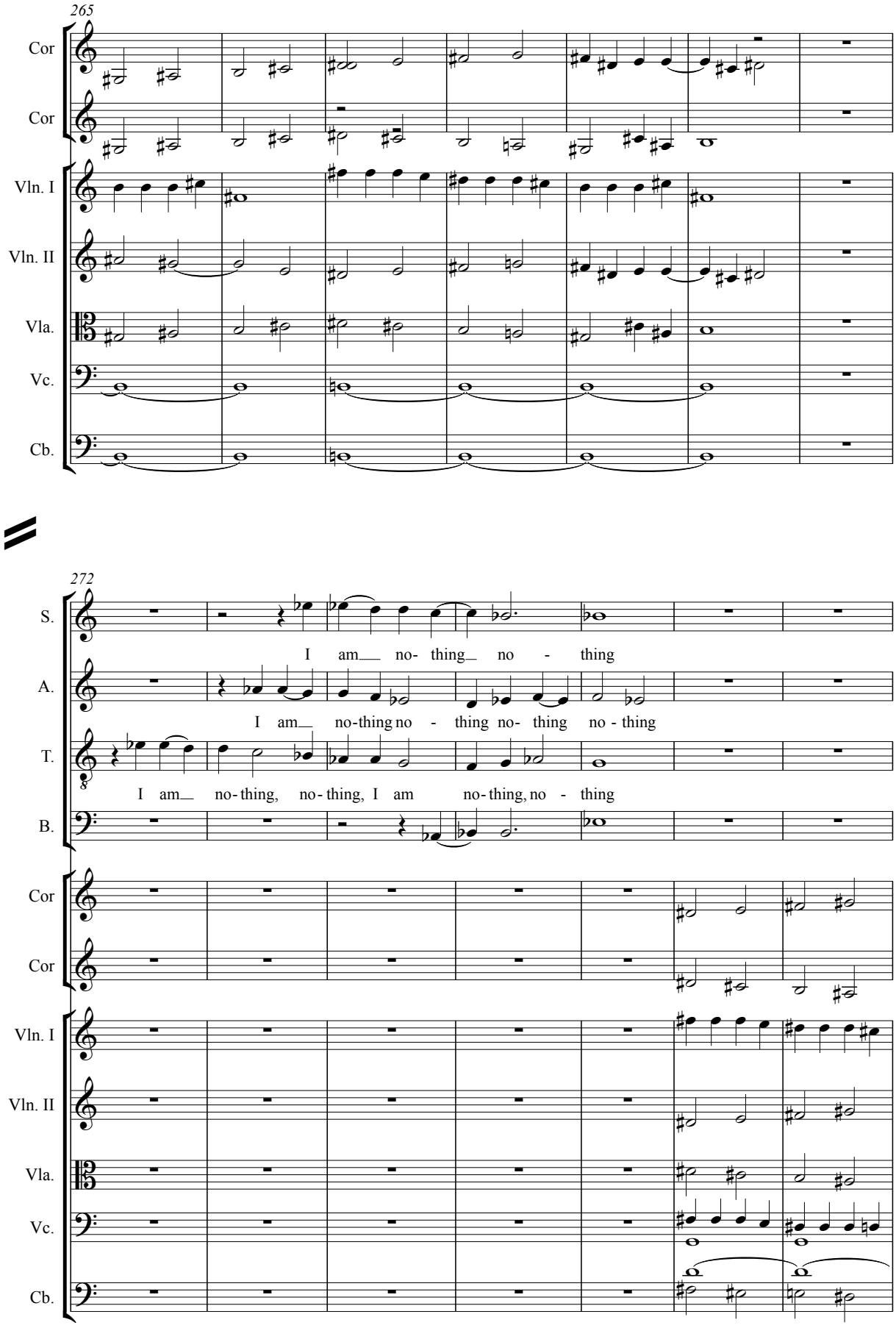

231
Fl.
S.
ev-er-y hid-den truth I may have
A.
I may have
T.
cy I may have
B.
And know I may have
Pno.
S. D.

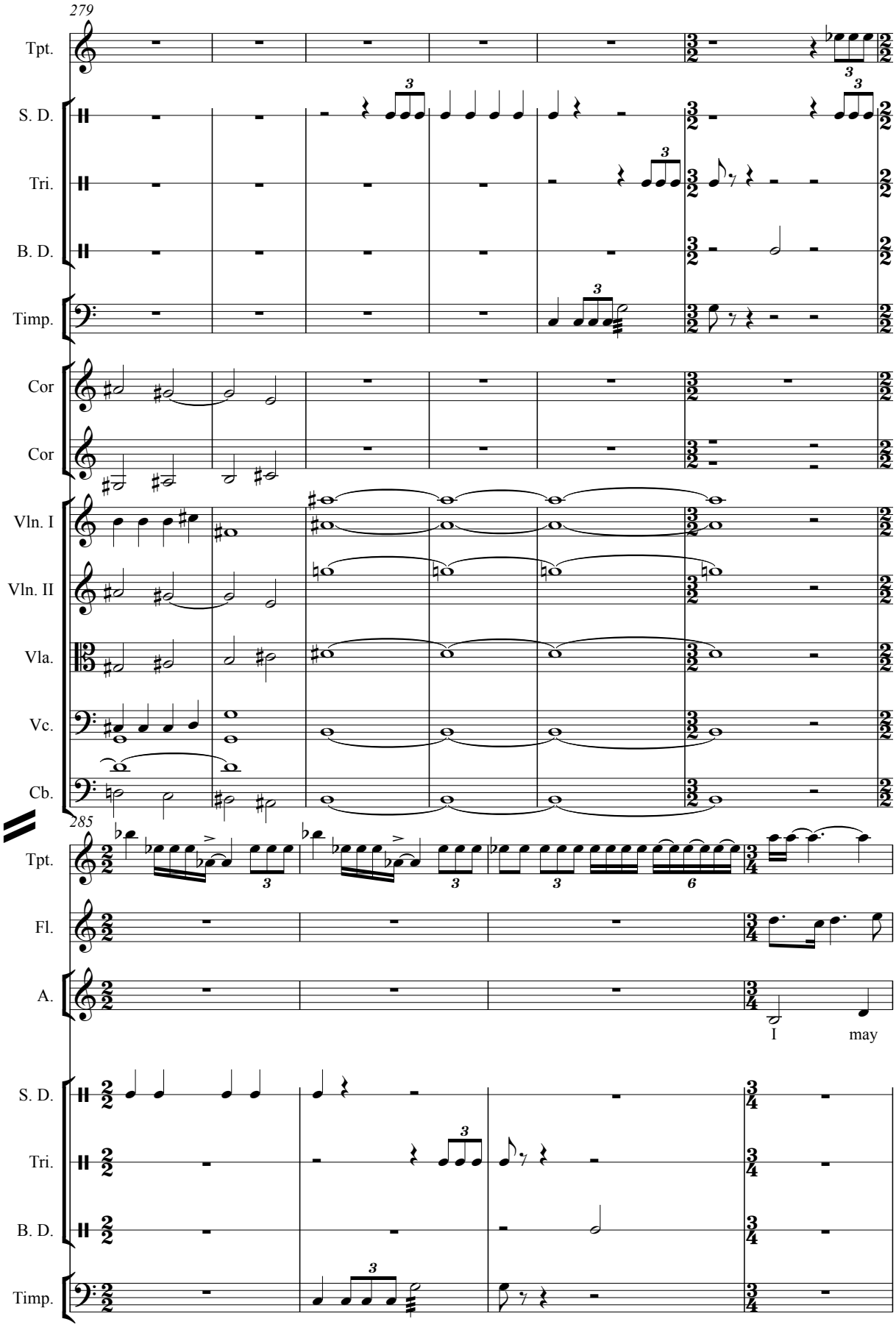

237
S.
faith strong e - nough to - move mount - - tains
A.
faith strong e - nough to - move mount - - tains
T.
faith strong e - nough to - move mount - - tains
B.
faith strong e - nough to - move mount - - tains
Pno.
move mount - - tains
move mount - - tains
S. D.
move mount - - tains
Tri.
tr

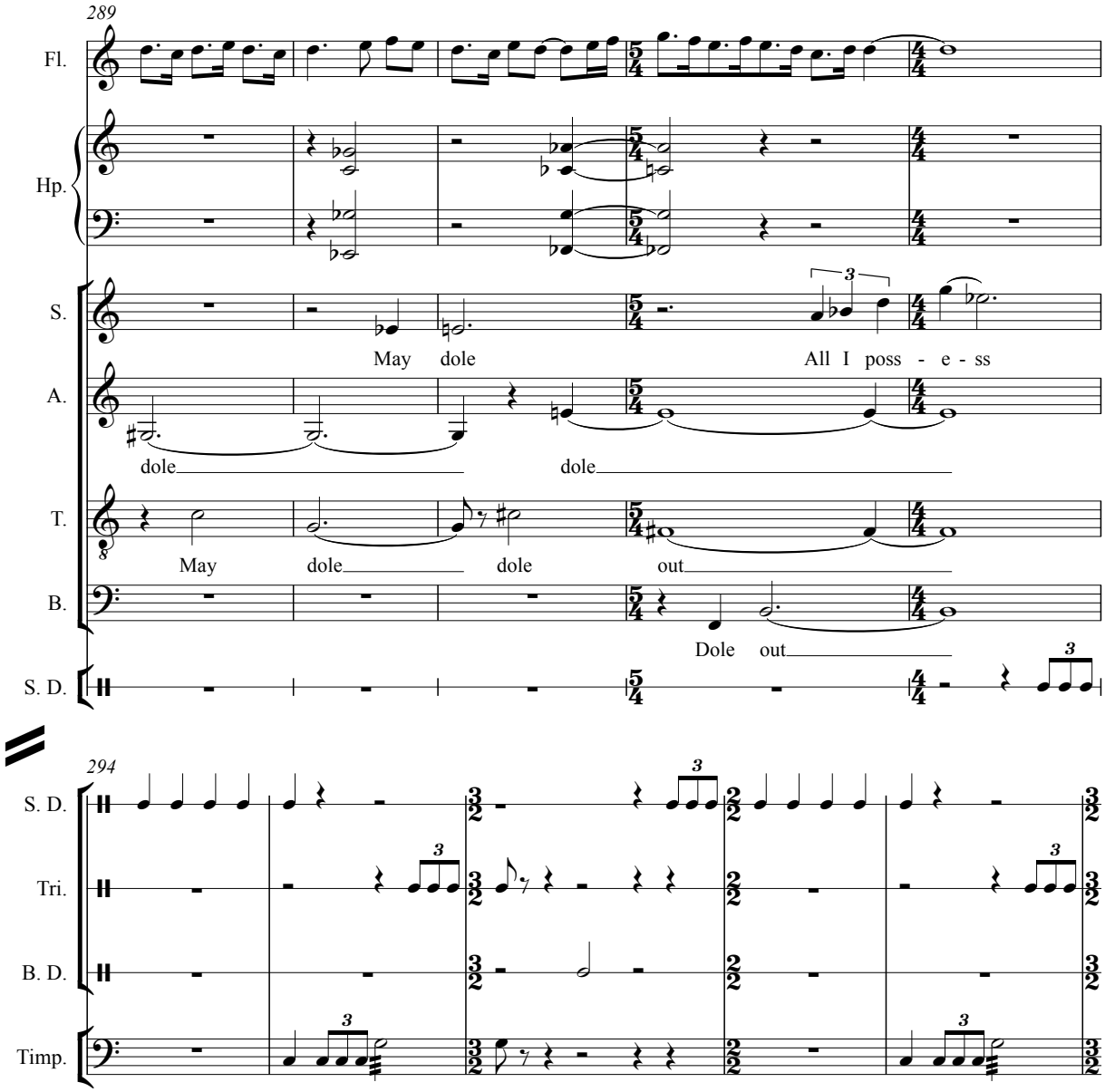

241
S. D.
Tri.
B. D.
Timp.
246
S. Solo
To
Hpsd.
S. D.
Tri.
B. D.
Timp.
B.
And was in-car-nate by the Ho - ly Ghost of the Vir-gin Ma - ry
250
S. Solo
the last syl-ab-le, syl-ab-le, to the
Hpsd.

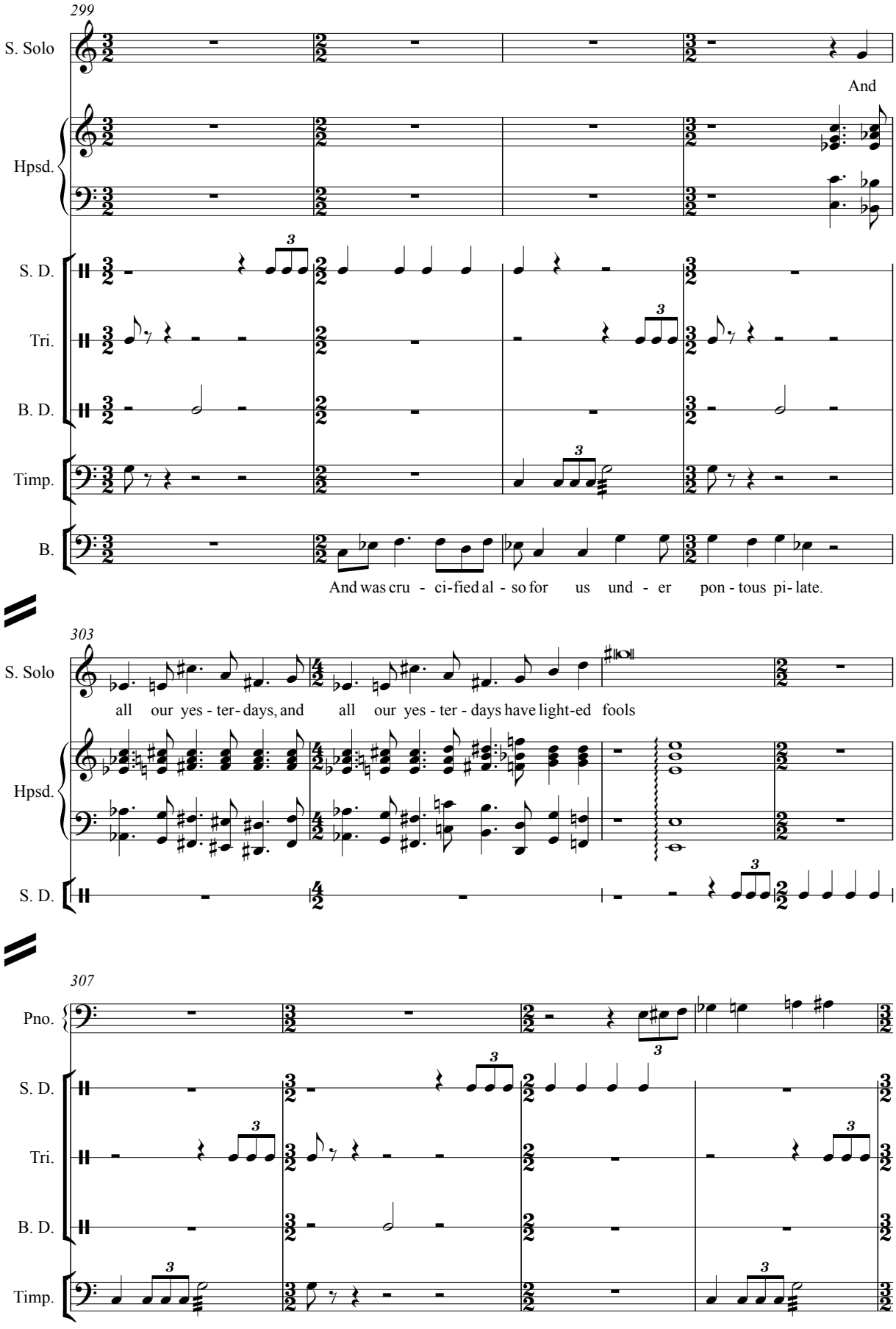

255
Fl.
Hp.
S. Solo
la - la - last syl - lyl - lyl - lyl - la - la - la - ble of re - cor - ded time
Hpsd.

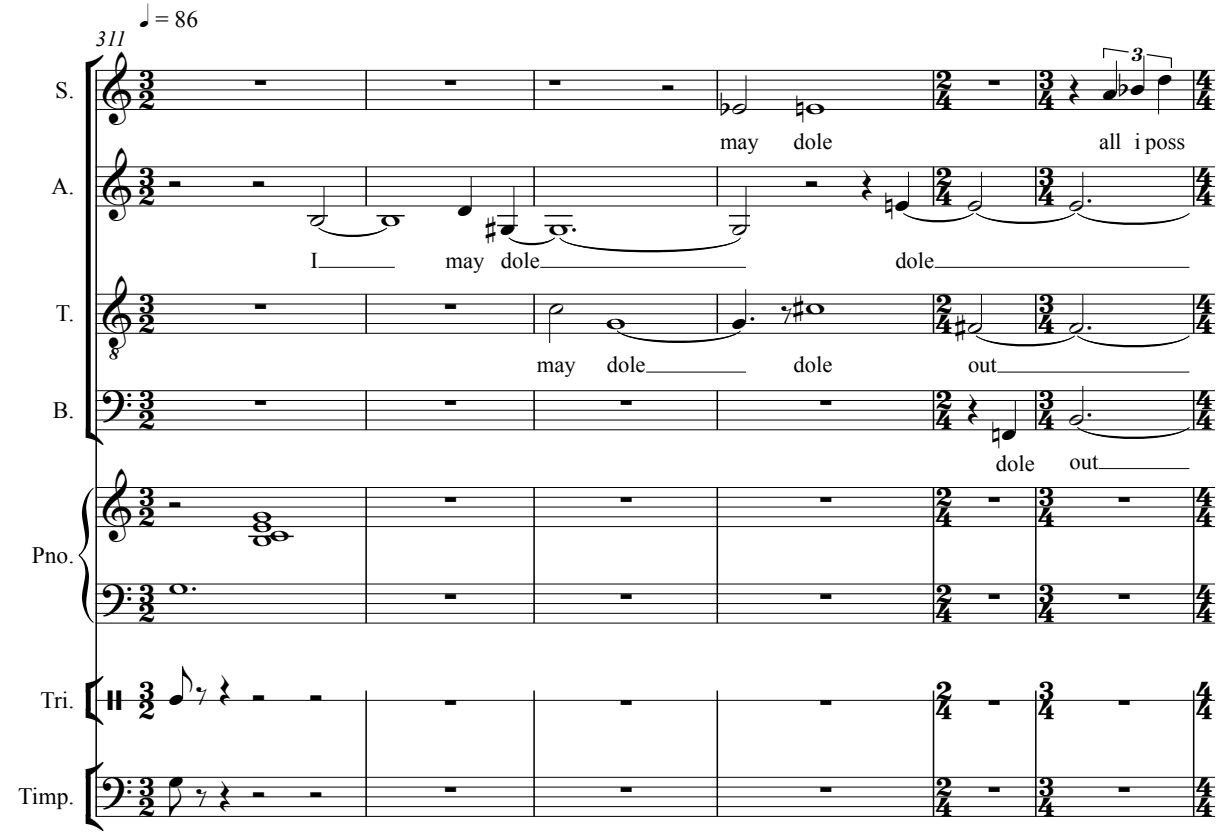

260
Fl.
Hp.
S.
But if i have no love
A.
But if i have no love
T.
But if i have no love
B.
But if i have no love
Tri.
Timp.
B.
And was made man
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.

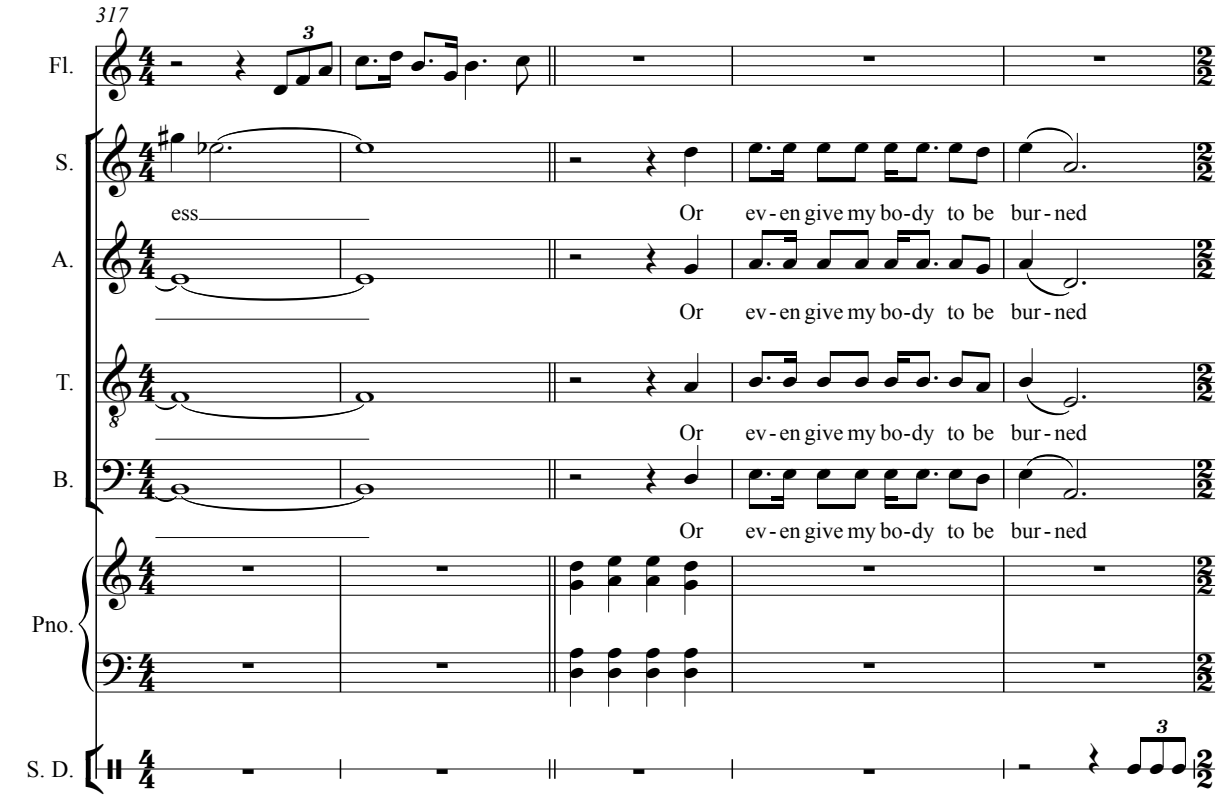

265
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.
272
S.
I am no- thing no - thing
A.
I am no-thing no - thing no- thing no - thing
T.
I am no-thing, no-thing, I am no-thing, no - thing
B.
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.

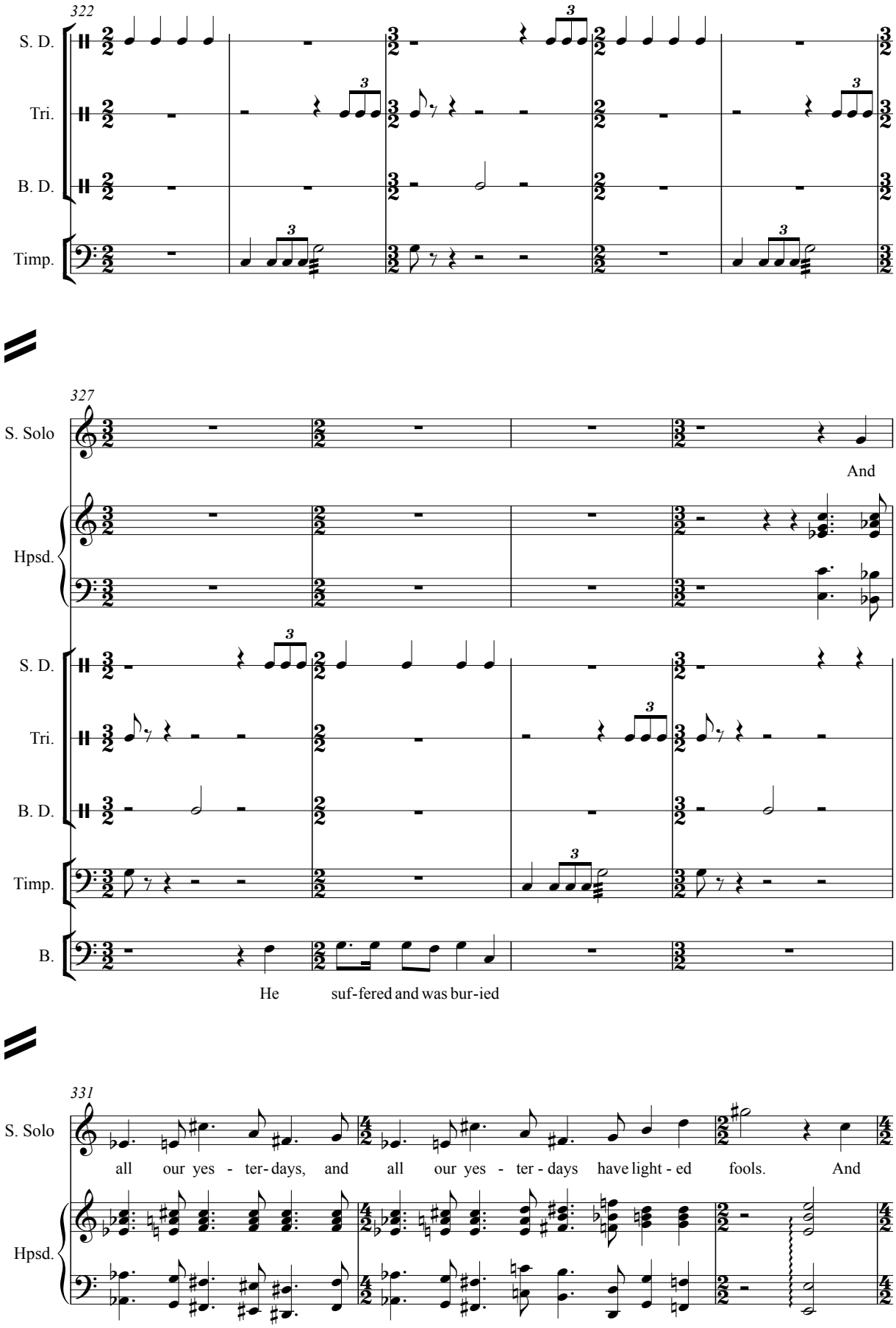

279
Tpt.
S. D.
Tri.
B. D.
Timp.
Cor
Cor
Vln. I
Vln. II
Vla.
Vc.
Cb.
285
Tpt.
Fl.
A.
I
may
S. D.
Tri.
B. D.
Timp.

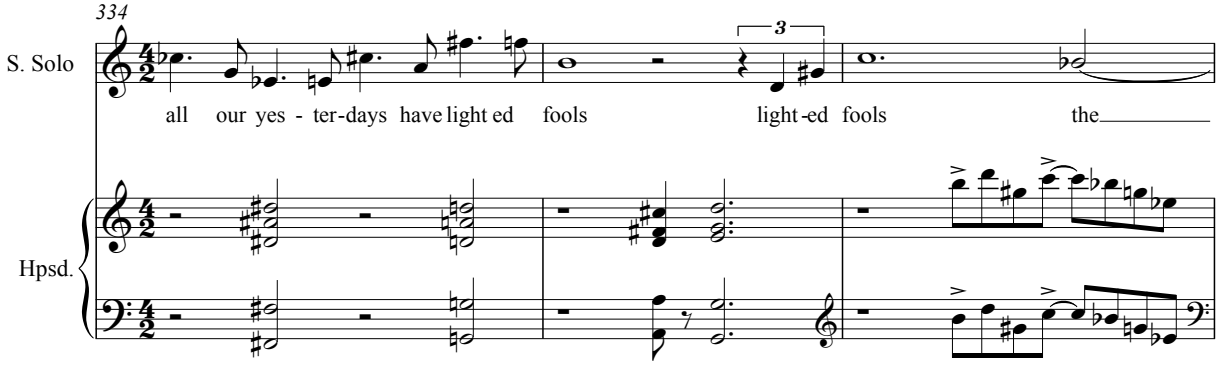

289
Fl.
Hp.
S.
A.
T.
B.
S. D.
May dole All I poss - e - ss
dole dole
May dole dole out
Dole out
294
S. D.
Tri.
B. D.
Timp.

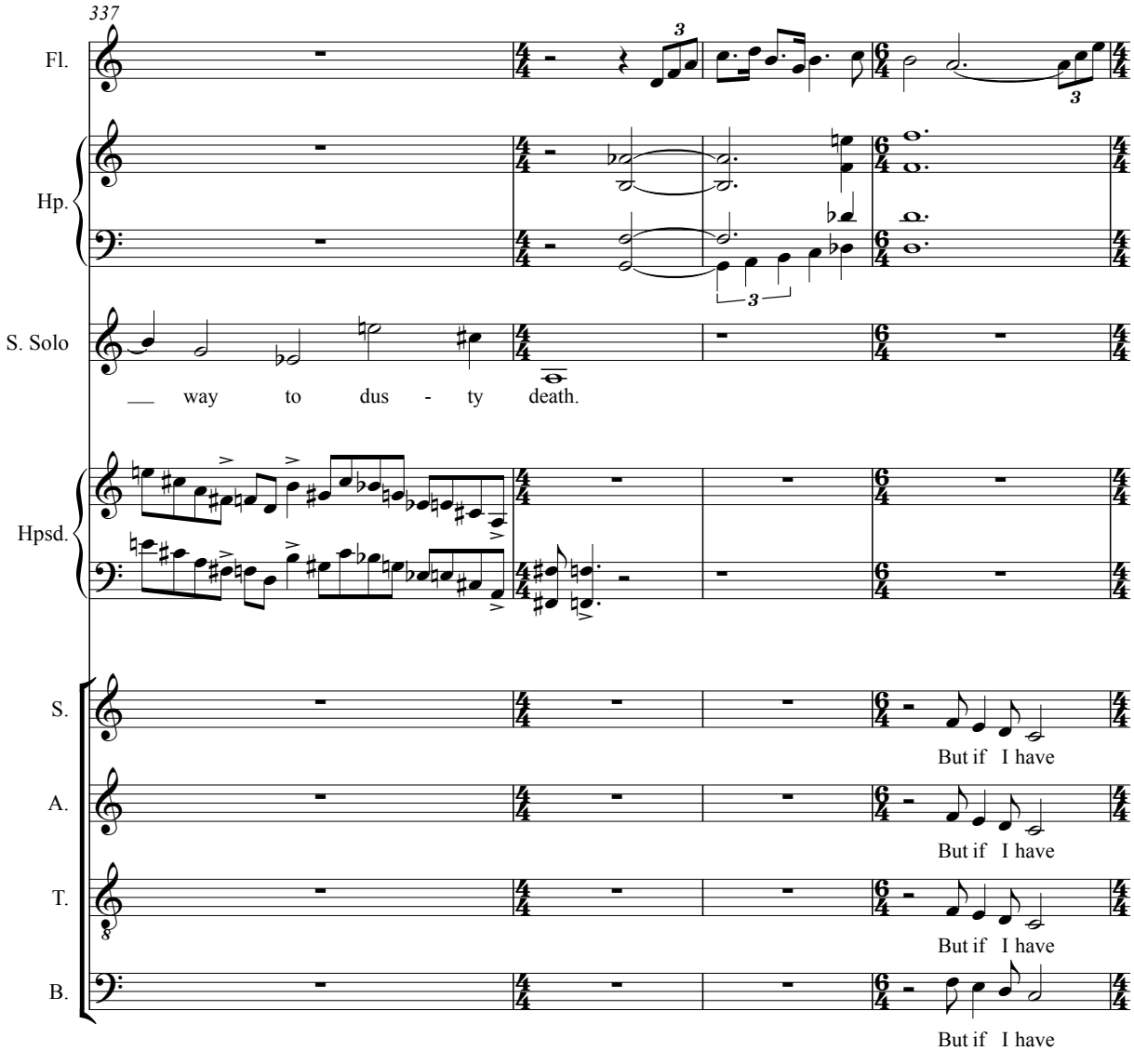

299
S. Solo
And
Hpsd.
S. D.
Tri.
B. D.
Timp.
B.
And was cru - ci-fied al - so for us und - er pon - tous pi- late.
303
S. Solo
all our yes - ter- days, and all our yes - ter - days have light-ed fools
Hpsd.
S. D.
307
Pno.
S. D.
Tri.
B. D.
Timp.

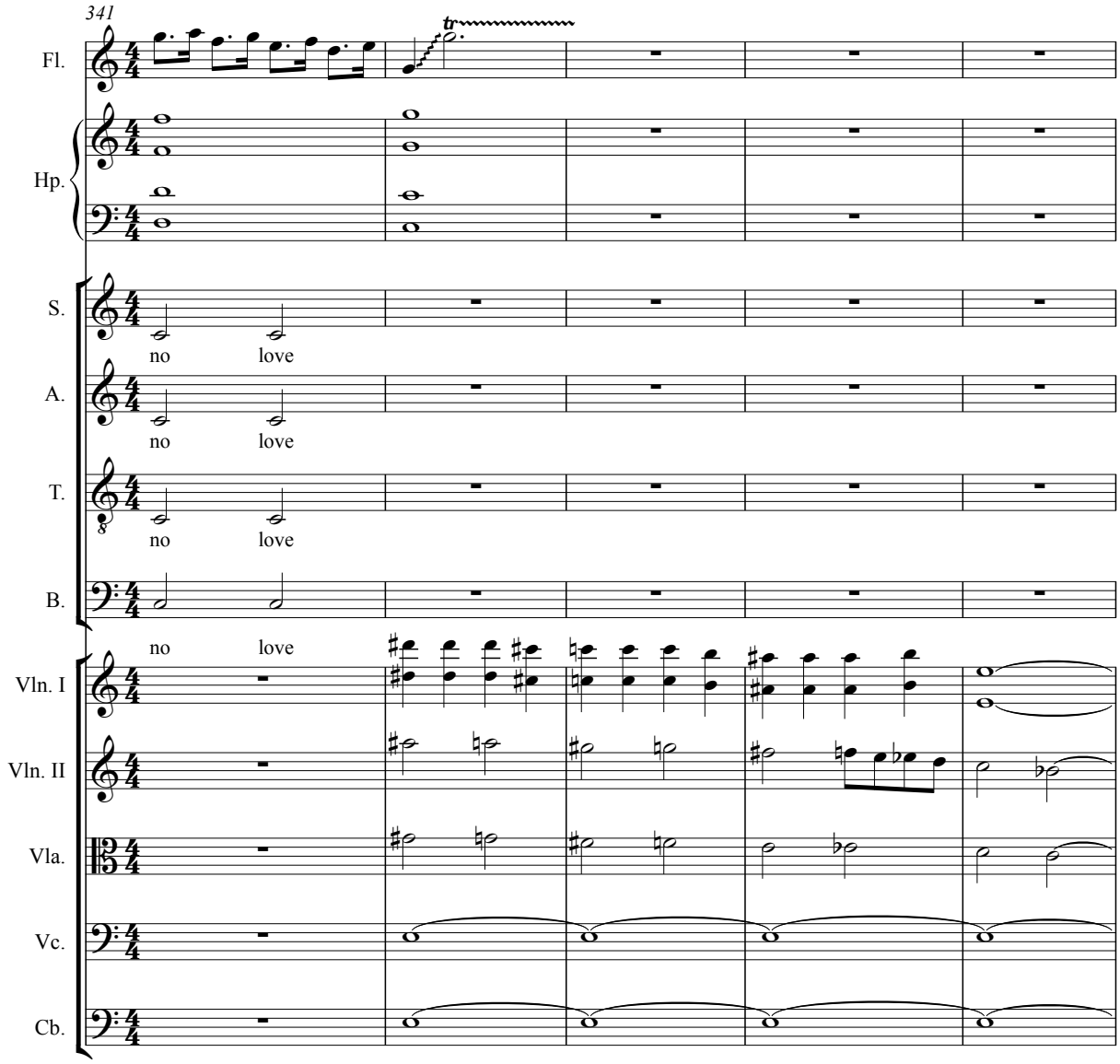

♩ = 86
311
S.
A.
T.
B.
Pno.
Tri.
Timp.
may dole all i poss
I may dole dole
may dole dole out
dole out

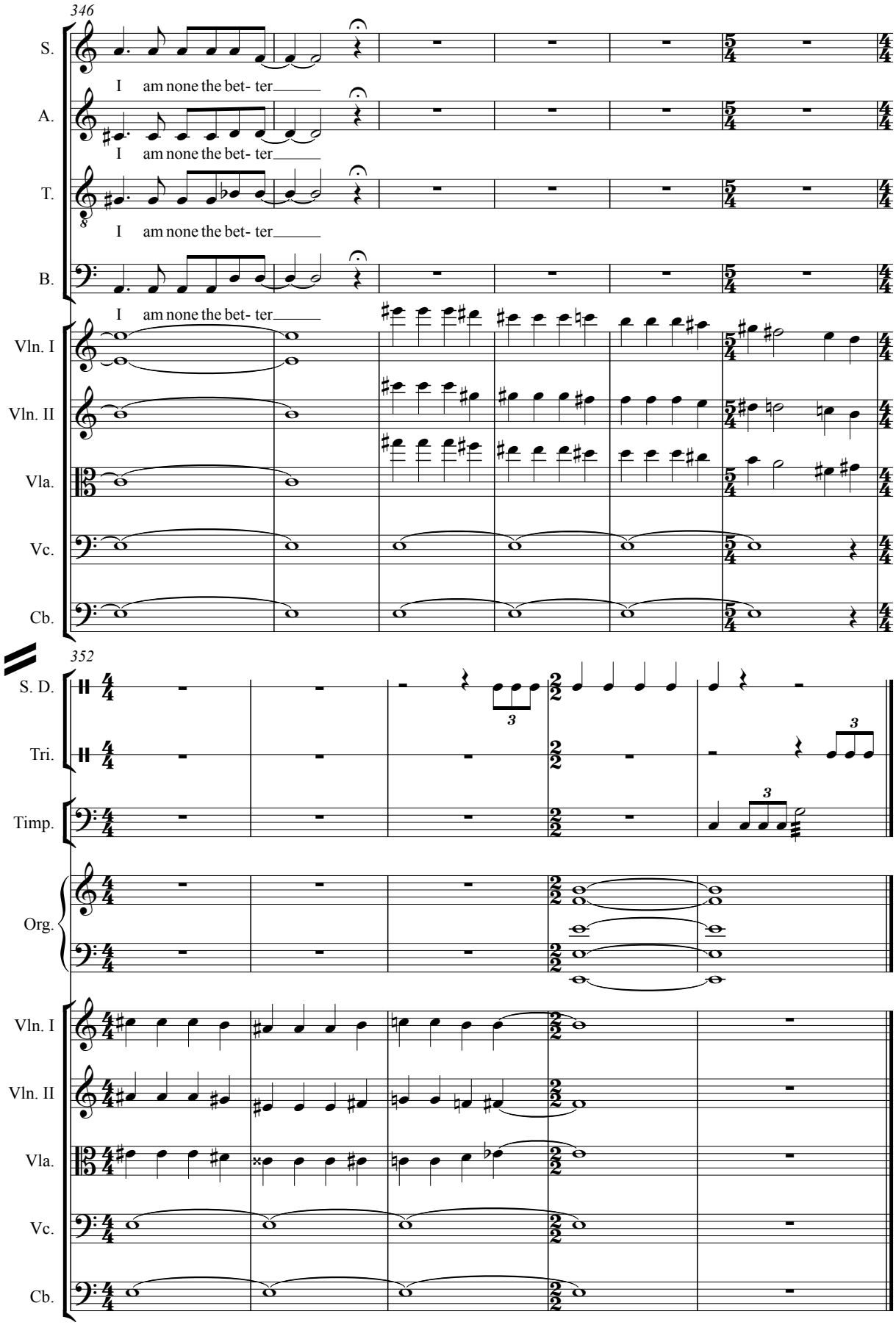

317
Fl.
S.
A.
T.
B.
Pno.
S. D.
ess
Or ev - en give my bo-dy to be bur - ned
Or ev - en give my bo-dy to be bur - ned
Or ev - en give my bo-dy to be bur - ned
Or ev - en give my bo-dy to be bur - ned


322
S. D.
Tri.
B. D.
Timp.
327
S. Solo
And
Hpsd.
S. D.
Tri.
B. D.
Timp.
B.
He suf-fered and was bur-ied
331
S. Solo
all our yes - ter-days, and all our yes - ter - days have light - ed fools. And
Hpsd.


334
S. Solo
all our yes - ter-days have light ed fools light -ed fools the
Hpsd.


337
Fl.
Hp.
S. Solo
way to dus - ty death.
Hpsd.
S.
But if I have
A.
But if I have
T.
But if I have
B.
But if I have


341
Fl.
Hp.
S.
no love
A.
no love
T.
no love
B.
no love
Vln. I
Vln. II
Vla.
Vc.
Cb.


346
S.
A.
T.
B.
I am none the bet- ter
I am none the bet- ter
I am none the bet- ter
I am none the bet- ter
Vln. I
Vln. II
Vla.
Vc.
Cb.
352
S. D.
Tri.
Timp.
Org.
Vln. I
Vln. II
Vla.
Vc.
Cb.

Secunda Pars

To continue from Prima Pars

Gregory Clifton-Smith

♩ = 86

Side Drum

Triangle

Bass Drum

Timpani

mf

Alto Solo

There was a slow flush o - ve-r all hi-s bo - dy, he ru -

In the style of plainsong

Bass

And the third day he rose ag-ain acc-ord-ing to the script-ures

Tutti Strings

Violin

String Quartet

Vln 1 qrt

Vln II qrt

Vla qrt

Vc qrt

♩ = 86

Organ

10

A. Solo

bbed hi-s neck a-nd arms in an ex - press-ion of pu - re joy, and said this is why i wen to Pri- son and its

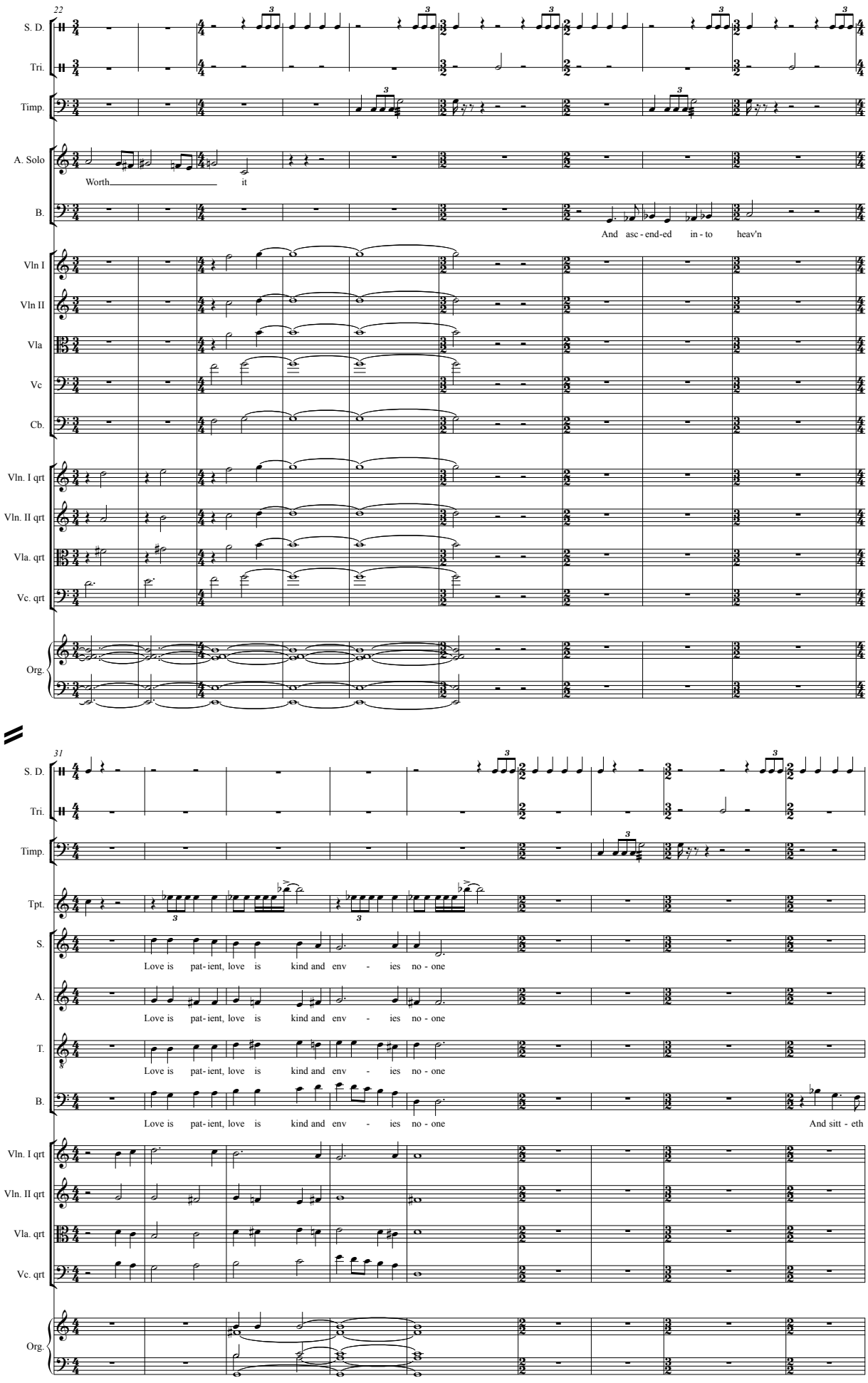
Vln. I qrt

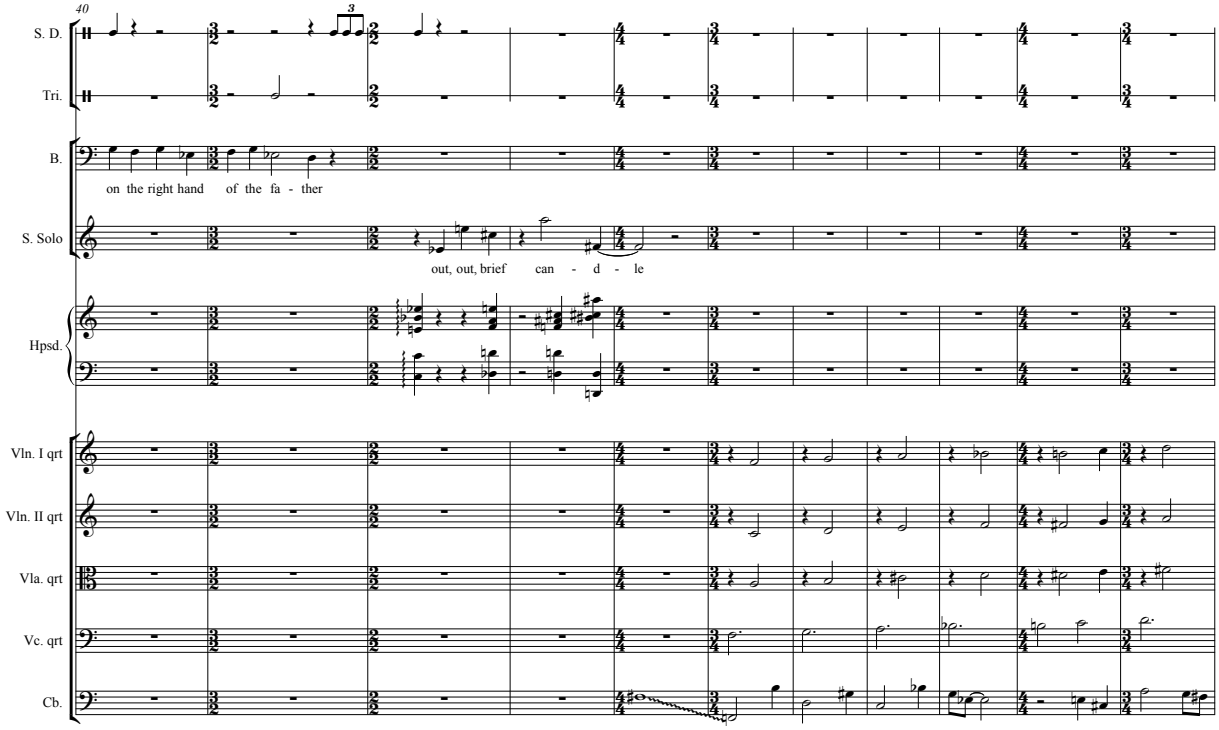
Vln. II qrt

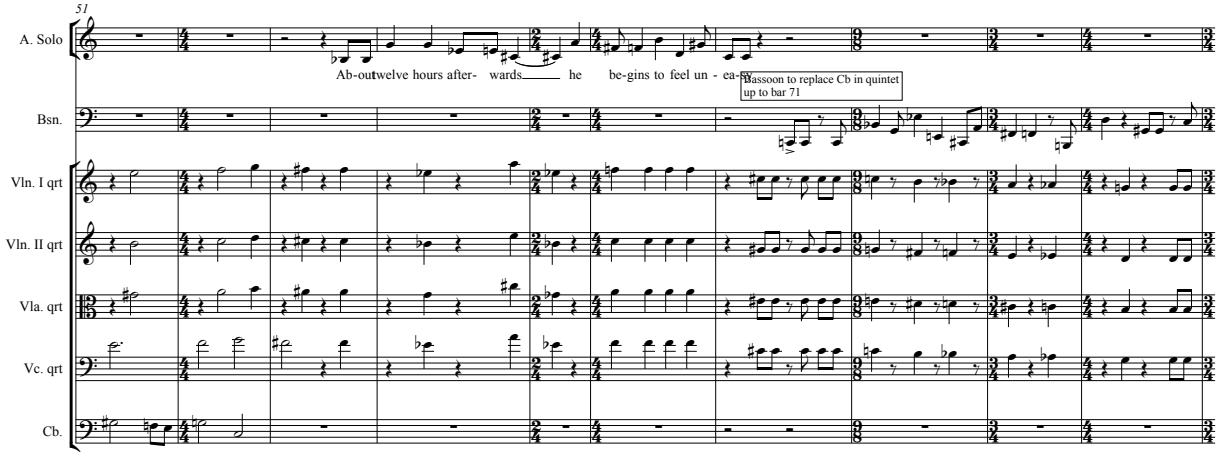
Vla. qrt

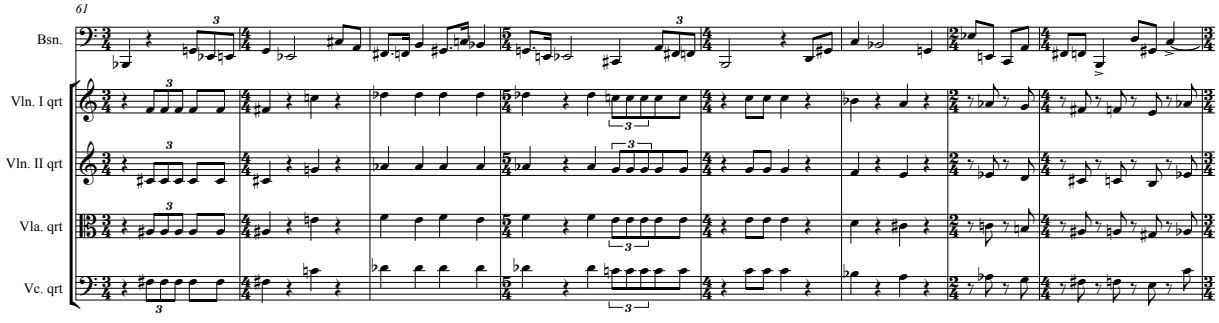
Vc. qrt

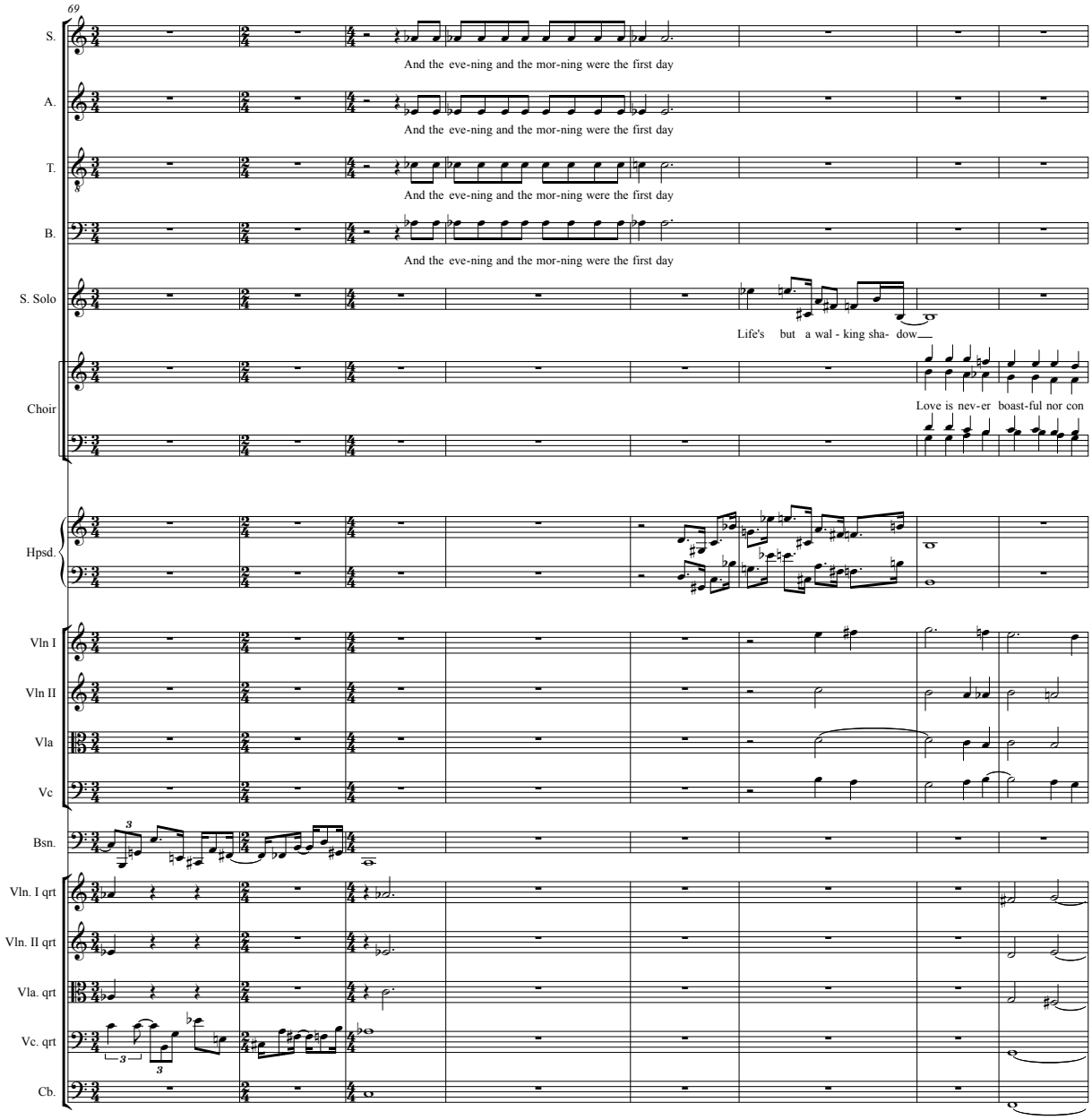
Org.

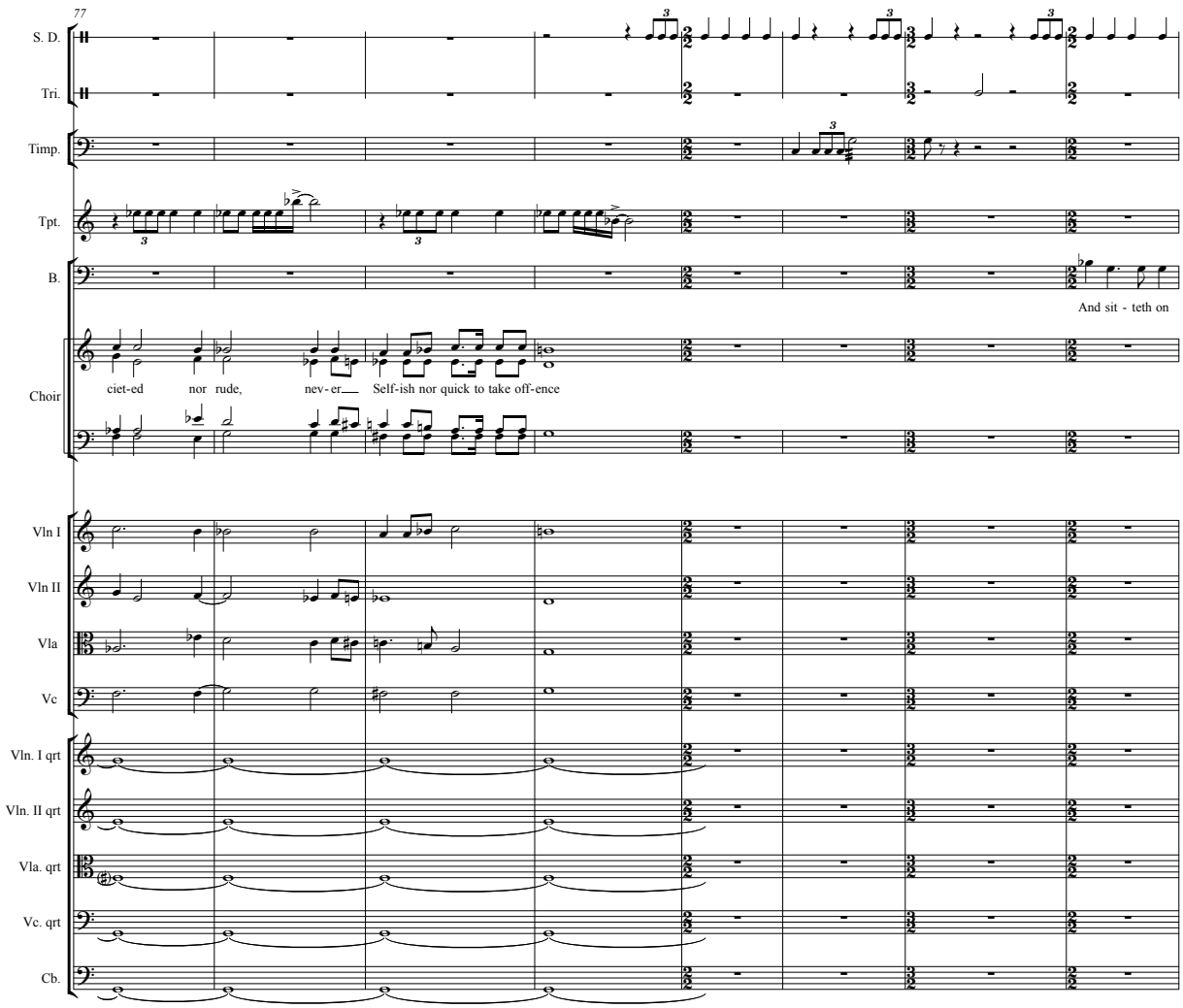

22
S. D.
Tri.
Timp.
A. Solo
Worth it
B.
And asc - end-ed in - to heav'n
Vln I
Vln II
Vla
Vc
Cb.
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Org.
31
S. D.
Tri.
Timp.
Tpt.
S.
Love is pat- ient, love is kind and env - ies no - one
A.
Love is pat- ient, love is kind and env - ies no - one
T.
Love is pat- ient, love is kind and env - ies no - one
B.
Love is pat- ient, love is kind and env - ies no - one
And sitt - eth
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Org.

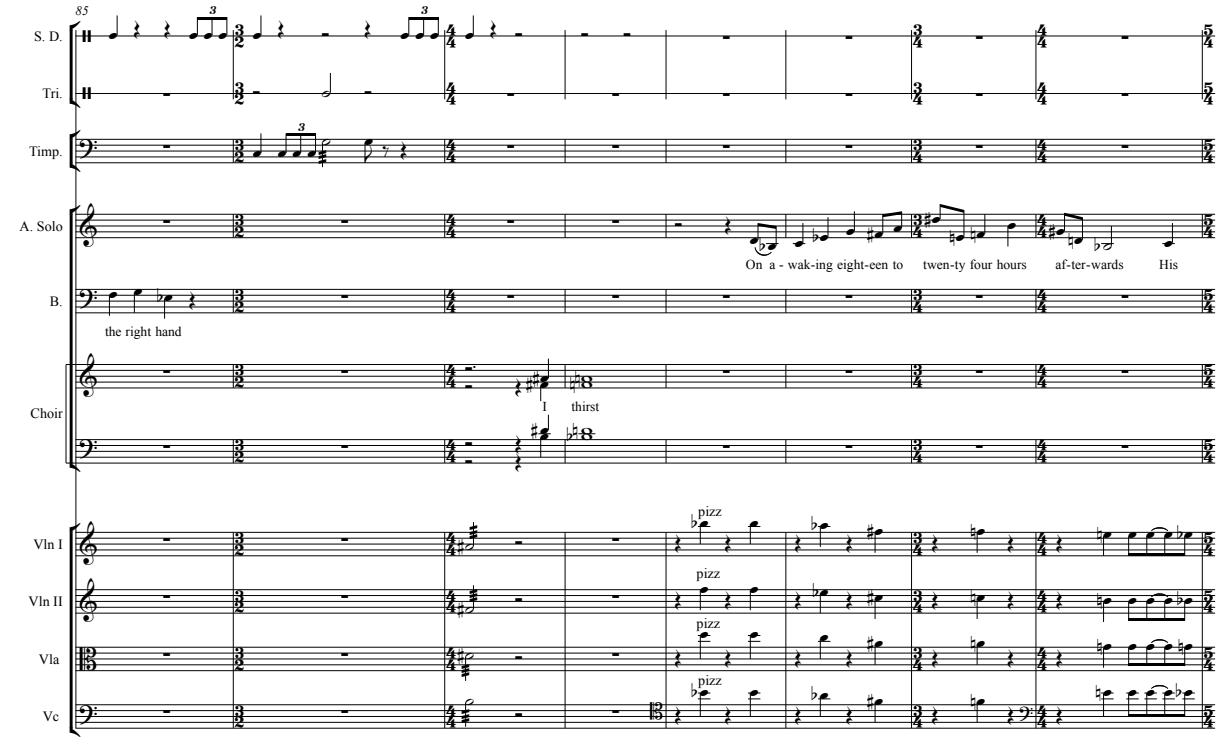

40
S. D.
Tri.
B.
on the right hand of the fa - ther
S. Solo
out, out, brief can - d - le
Hpsd.
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.

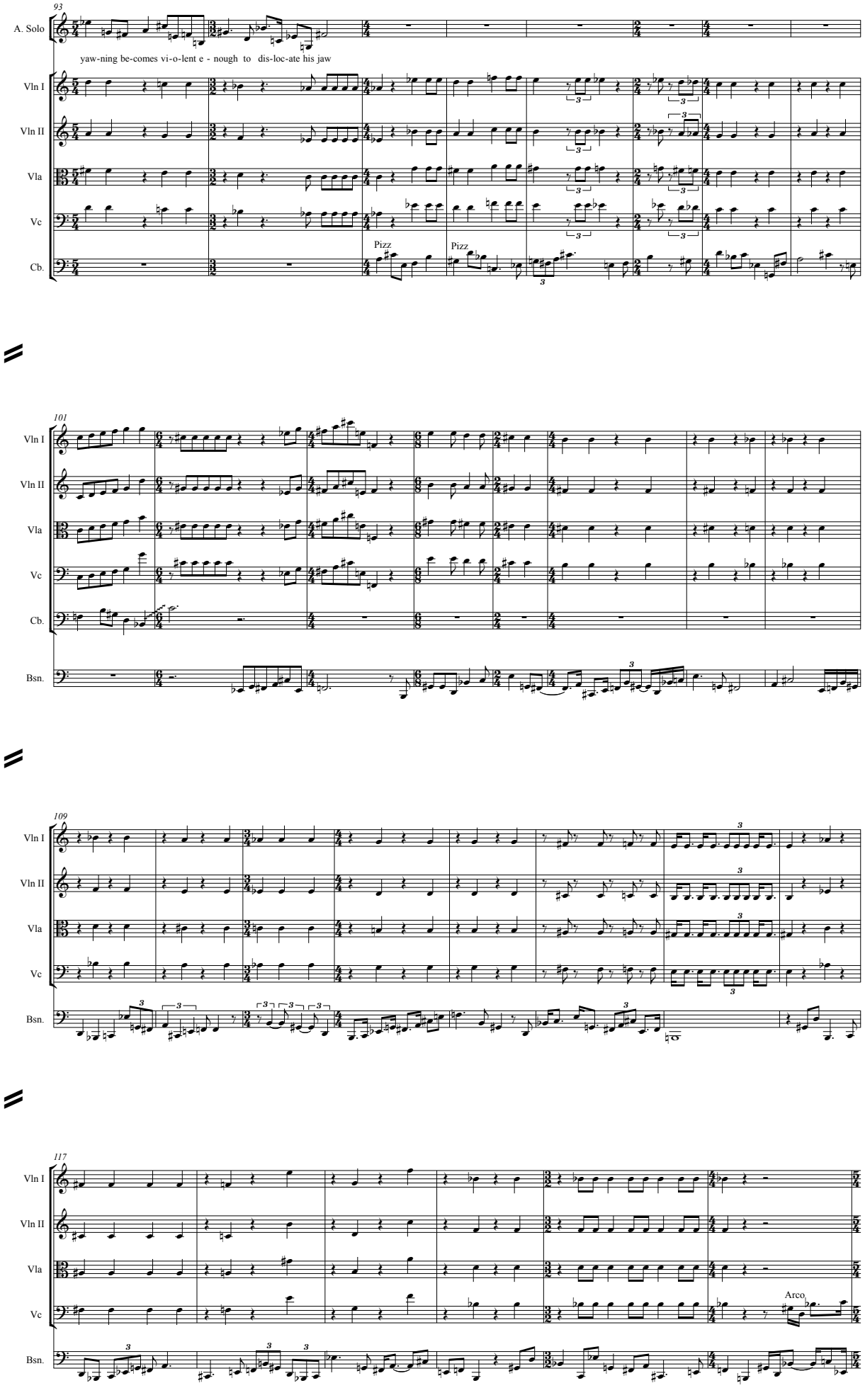

51
A. Solo
Ab-outwelve hours after- wards he be-gins to feel un - ea-sy
Bassoon to replace Cb in quintet up to bar 71
Bsn.
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.

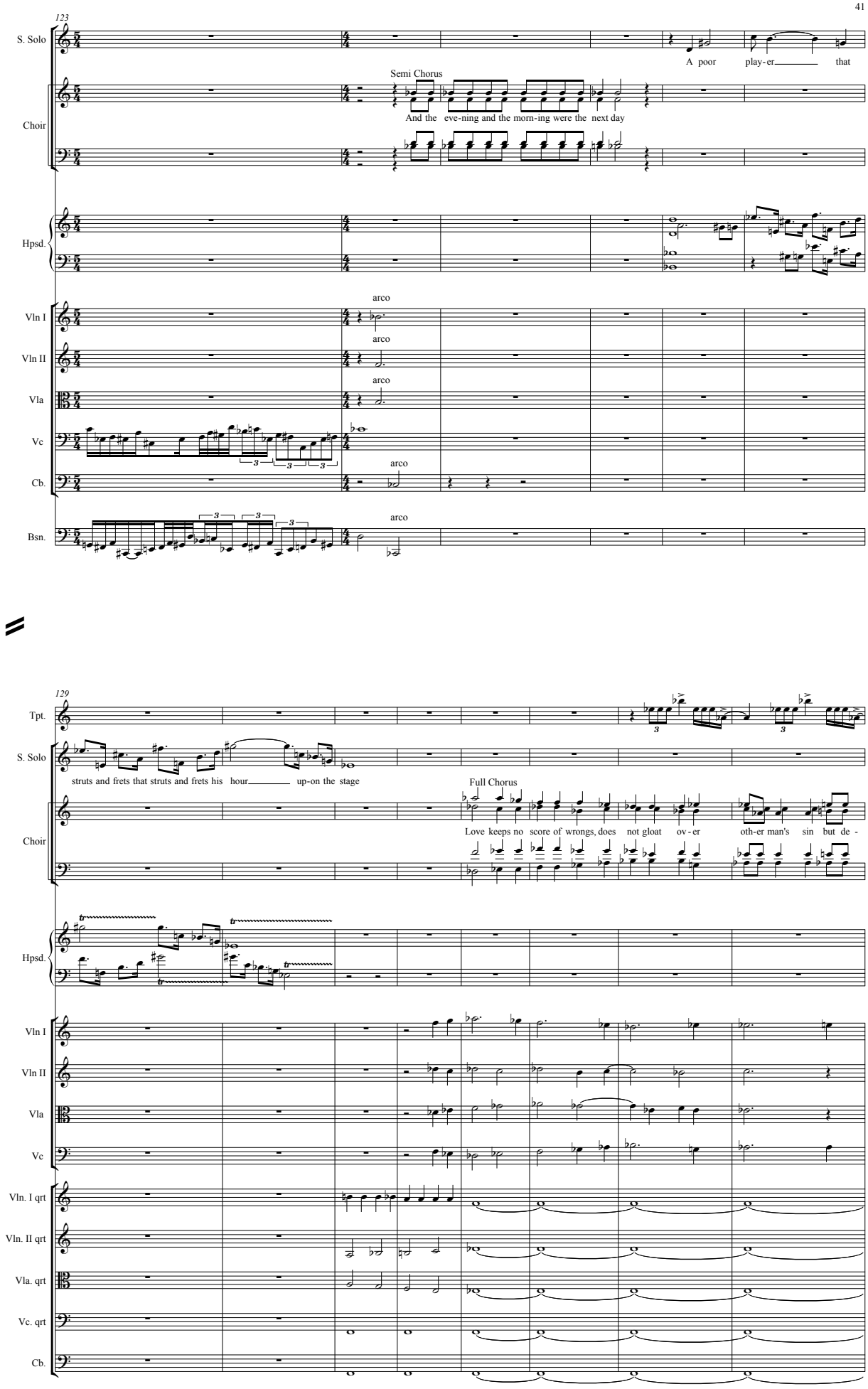

61
Bsn.
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt

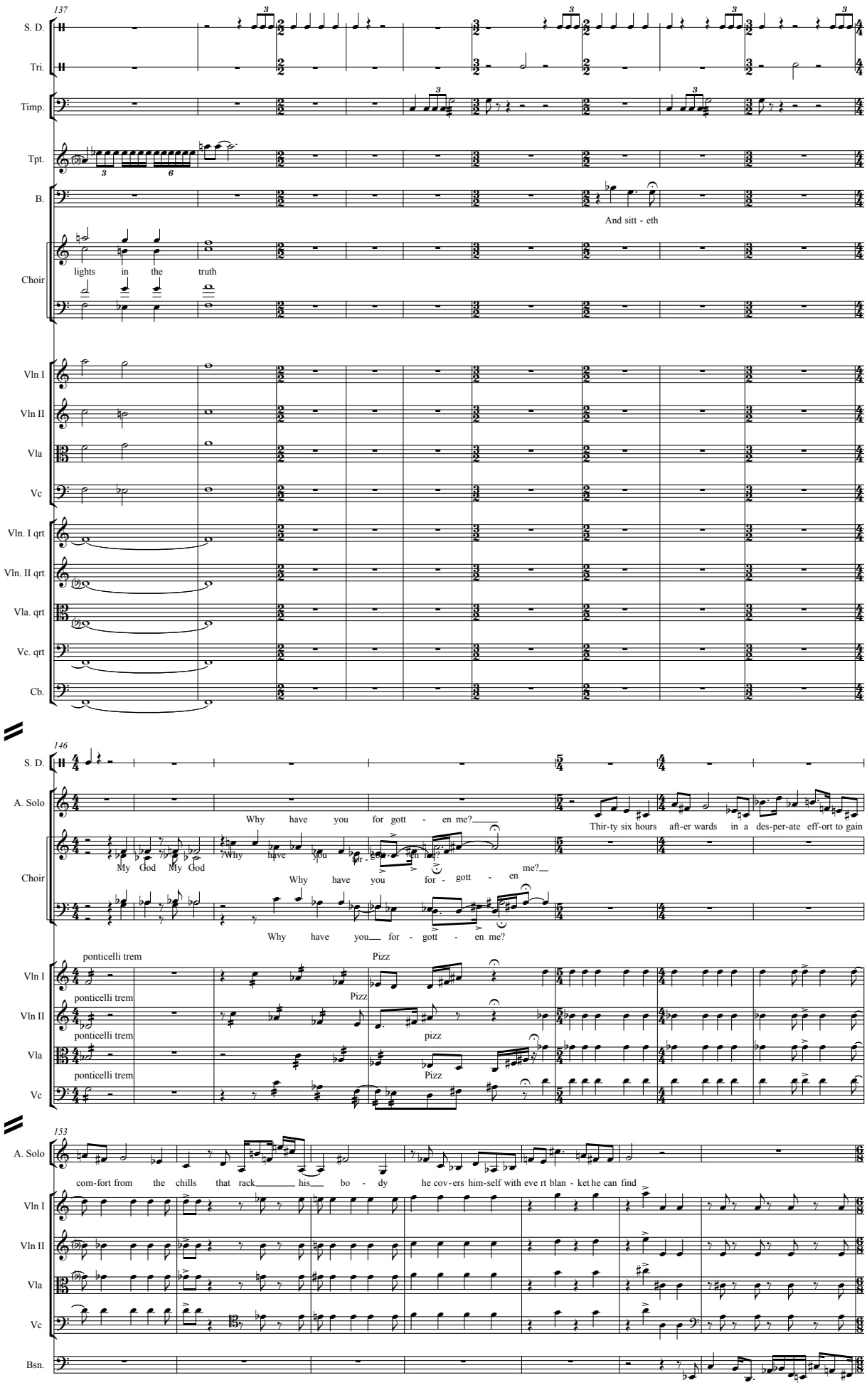

69
S.
And the eve-ning and the mor-ning were the first day
A.
And the eve-ning and the mor-ning were the first day
T.
And the eve-ning and the mor-ning were the first day
B.
And the eve-ning and the mor-ning were the first day
S. Solo
Life's but a wal - king sha- dow
Choir
Love is nev-er boast-ful nor con
Hpsd.
Vln I
Vln II
Vla
Vc
Bsn.
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.

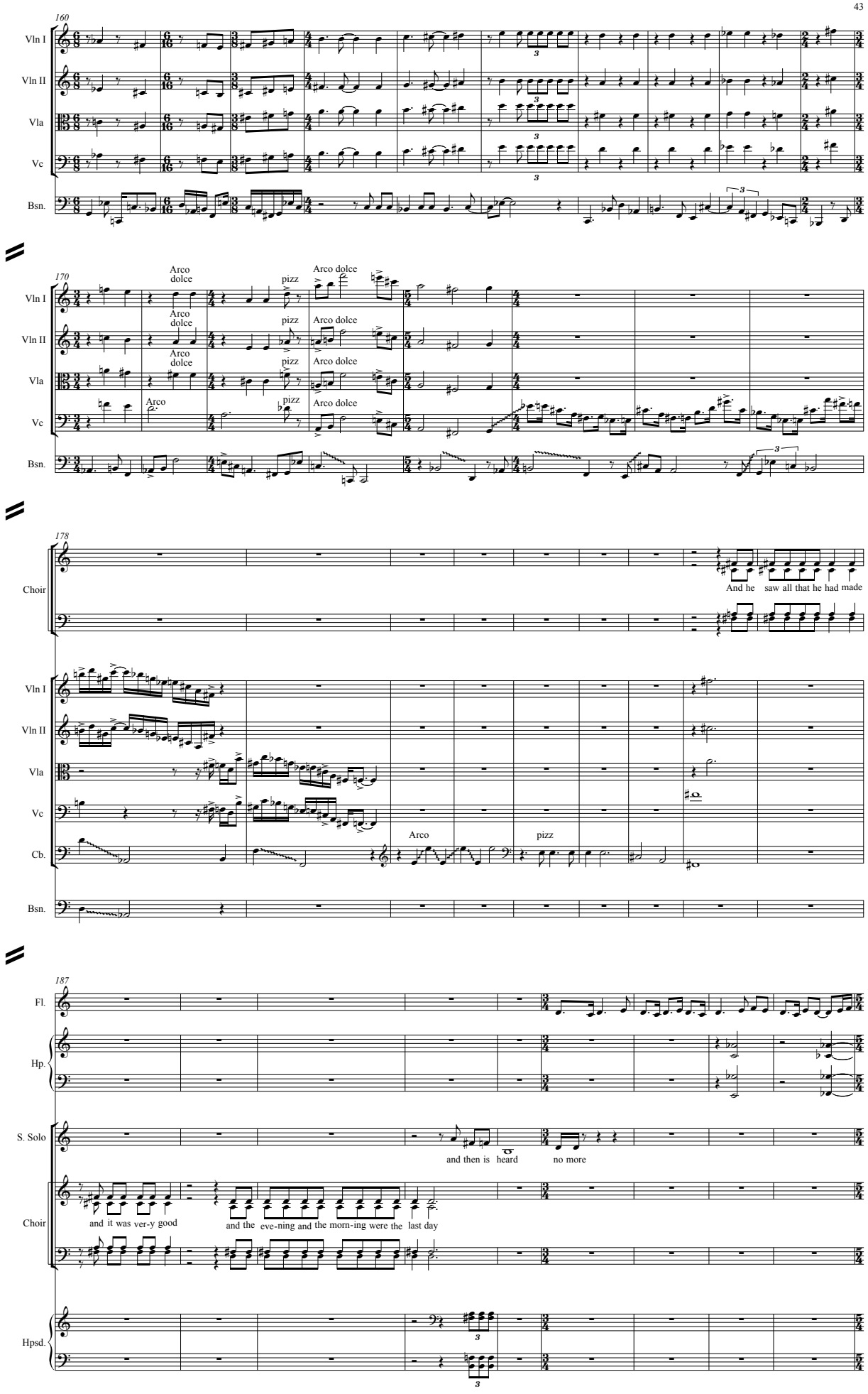

77
S. D.
Tri.
Timp.
Tpt.
B.
And sit - teth on
Choir
ciet-ed nor rude, nev-er— Self-ish nor quick to take off-ence
Vln I
Vln II
Vla
Vc
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.

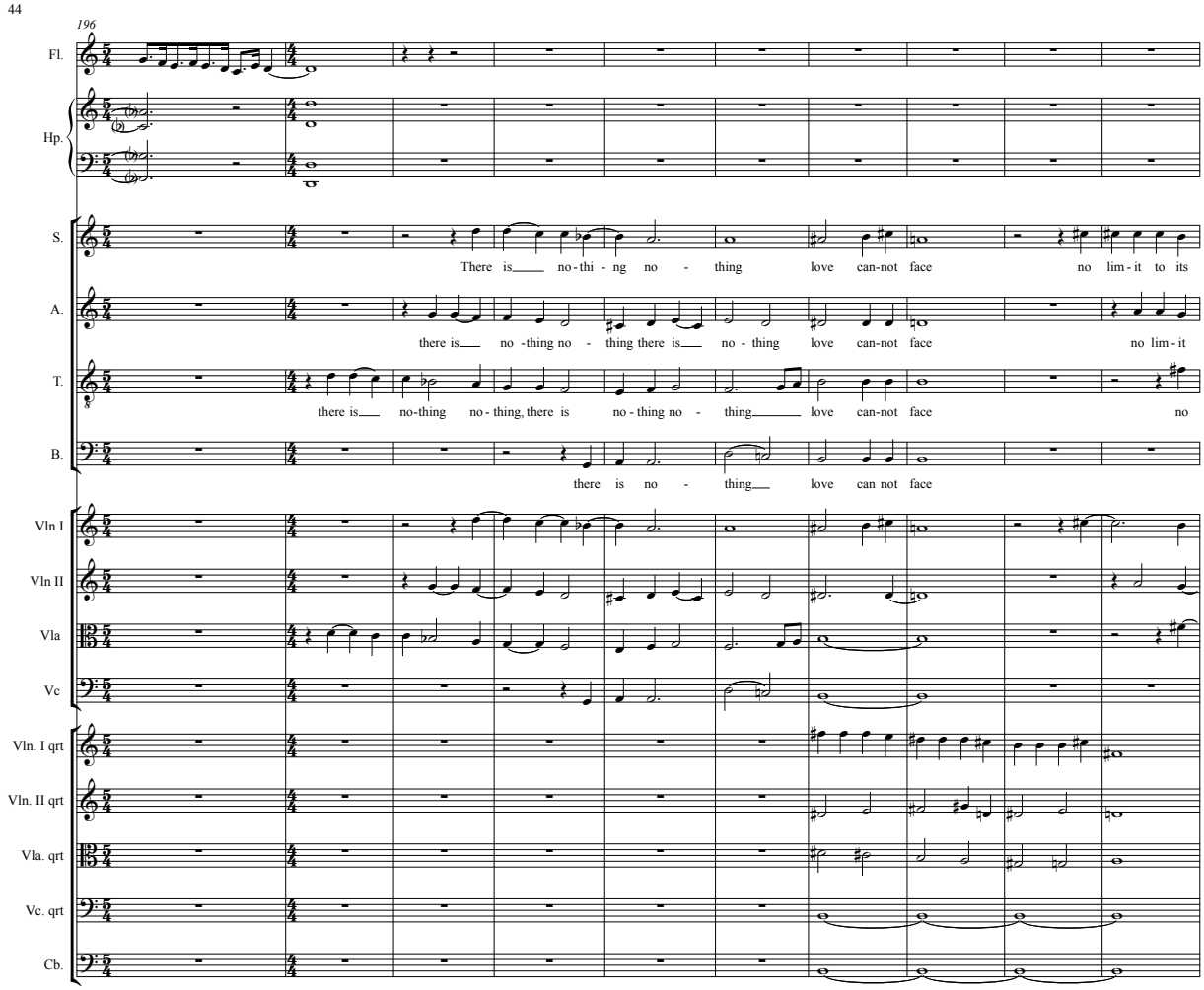

85
S. D.
Tri.
Timp.
A. Solo
On a - wak-ing eight-een to twen-ty four hours af-ter-wards His
B.
the right hand
Choir
I thirst
Vln I
pizz
Vln II
pizz
Vla
pizz
Vc
pizz

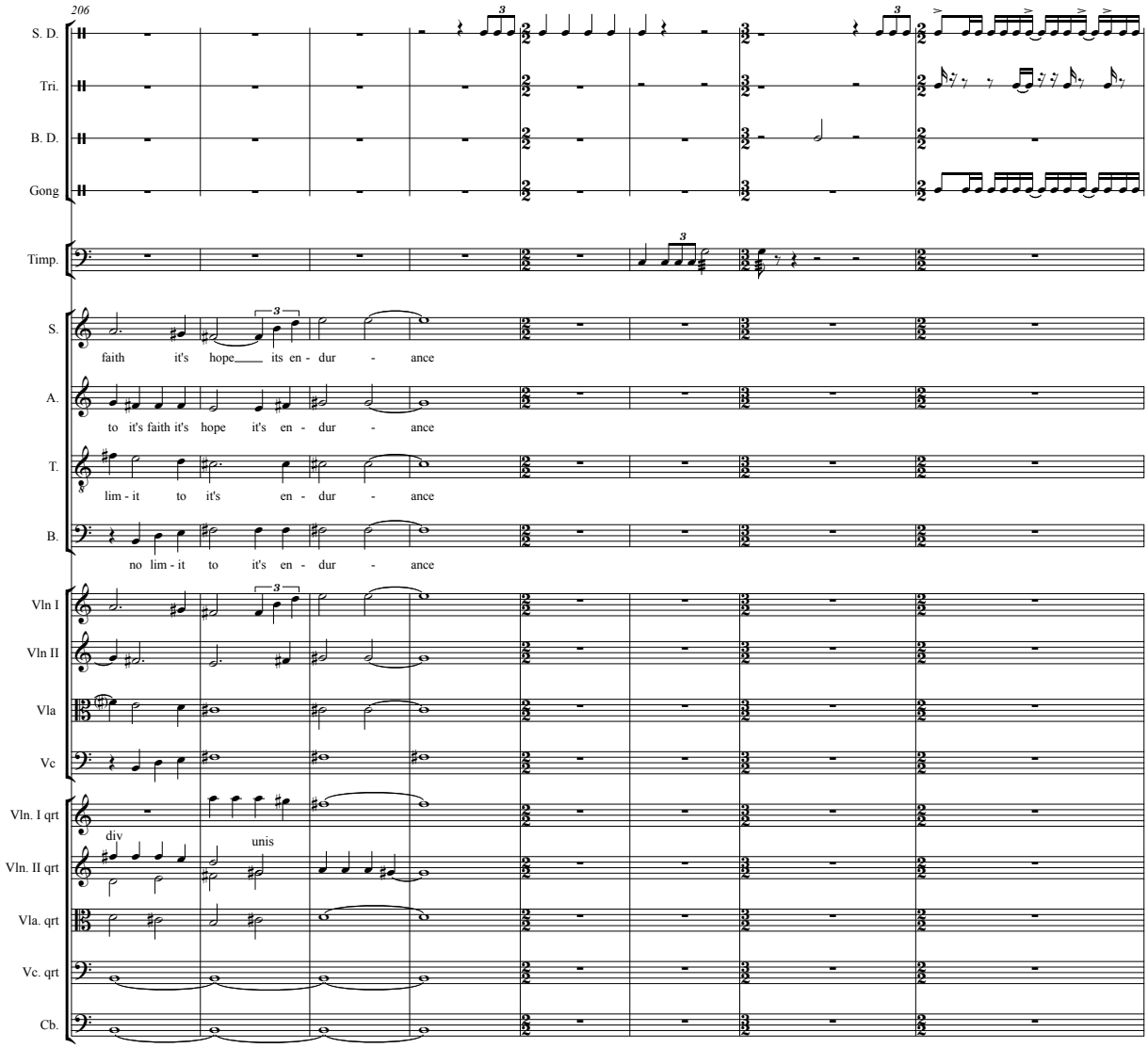

93
A. Solo
yaw-ning be-comes vi-o-lent e - nough to dis-loc-ate his jaw
Vln I
Vln II
Vla
Vc
Cb.
Pizz
Pizz
101
Vln I
Vln II
Vla
Vc
Cb.
Bsn.
109
Vln I
Vln II
Vla
Vc
Bsn.
117
Vln I
Vln II
Vla
Vc
Bsn.
Arco

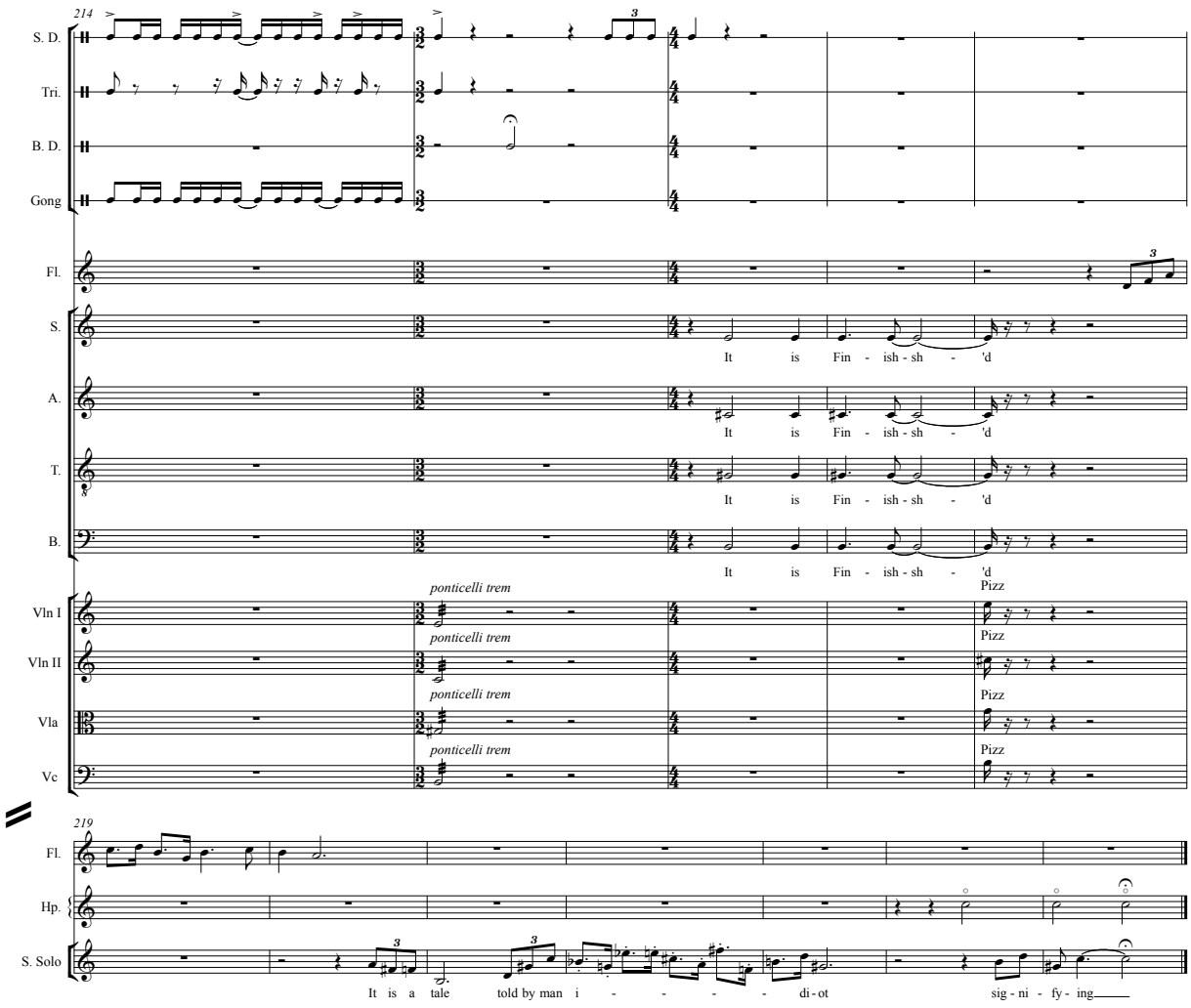

123
S. Solo
A poor play-er that
Choir
Semi Chorus
And the eve-ning and the morn-ing were the next day
Hpsd.
Vln I
arco
Vln II
arco
Vla
arco
Vc
arco
Cb.
arco
Bsn.
arco
129
Tpt.
S. Solo
struts and frets that struts and frets his hour up-on the stage
Choir
Full Chorus
Love keeps no score of wrongs, does not gloat ov-er oth-er man's sin but de -
Hpsd.
Vln I
Vln II
Vla
Vc
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.


137
S. D.
Tri.
Timp.
Tpt.
B.
And sitt - eth
Choir
lights in the truth
Vln I
Vln II
Vla
Vc
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.
146
S. D.
A. Solo
Why have you for gott - en me?
Thir-ty six hours aft-er wards in a des-per-ate eff-ort to gain
Choir
My God My God
Why have you for - gott - en me?
Why have you for gott - en me?
ponticelli trem
Pizz
Vln I
Vln II
Vla
Vc
153
A. Solo
com-fort from the chills that rack his bo - dy
he cov-ers him-self with eve rt blan - ket he can find
Vln I
Vln II
Vla
Vc
Bsn.


160
Vln I
Vln II
Vla
Vc
Bsn.
170
Arco dolce
pizz
Arco dolce
Arco
178
Choir
And he saw all that he had made
Cb.
Arco
pizz
187
Fl.
Hp.
S. Solo
and then is heard no more
and it was ver-y good
and the eve-ning and the morn-ing were the last day
Hpsd.

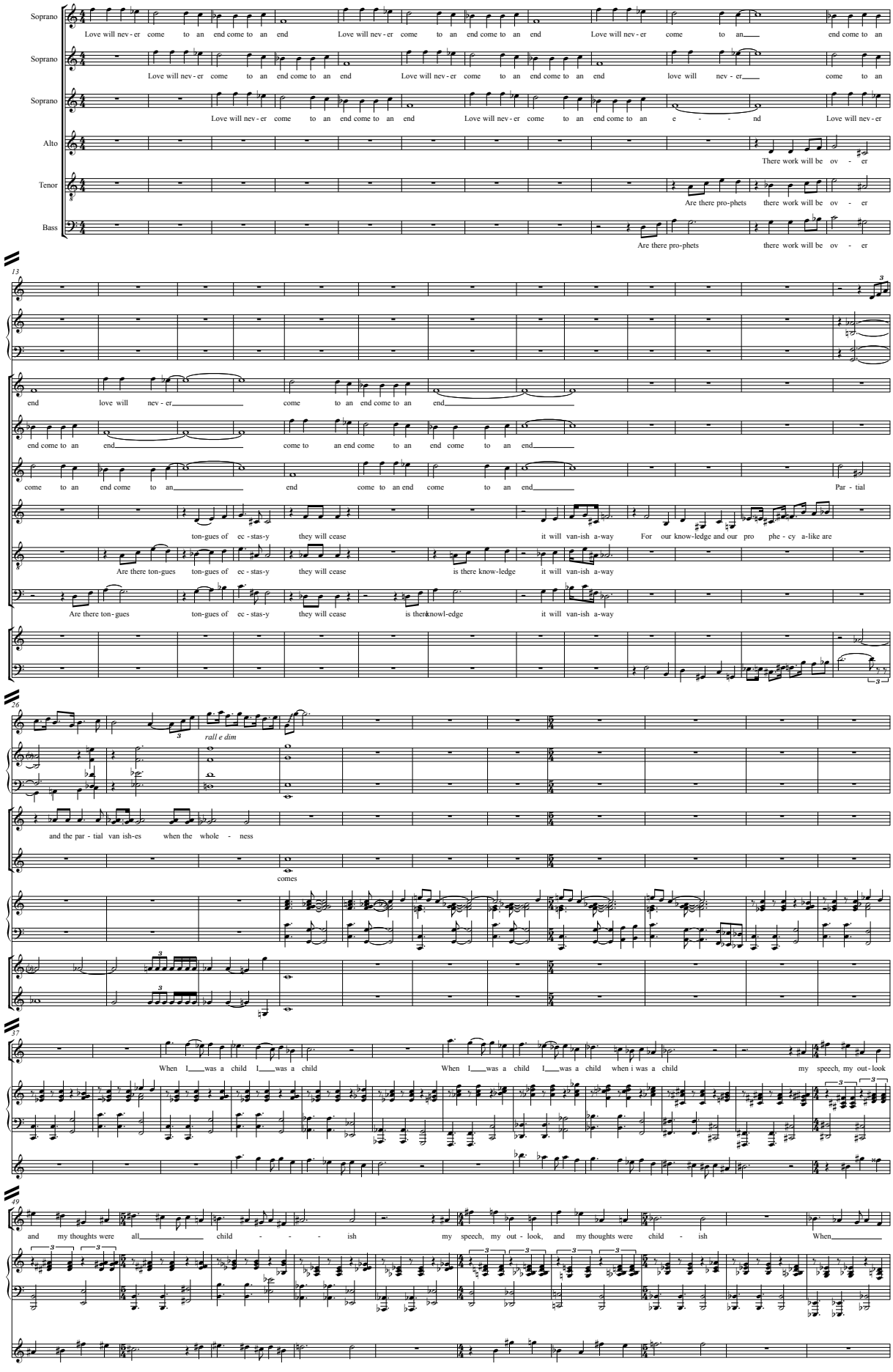

196
Fl.
Hp.
S.
There is no-thi - ng no - thing love can-not face no lim - it to its
A.
there is no -thing no - thing there is no - thing love can-not face no lim - it
T.
there is no-thing no - thing, there is no - thing no - thing love can-not face no
B.
there is no - thing love can not face
Vln I
Vln II
Vla
Vc
Vln. I qrt
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.

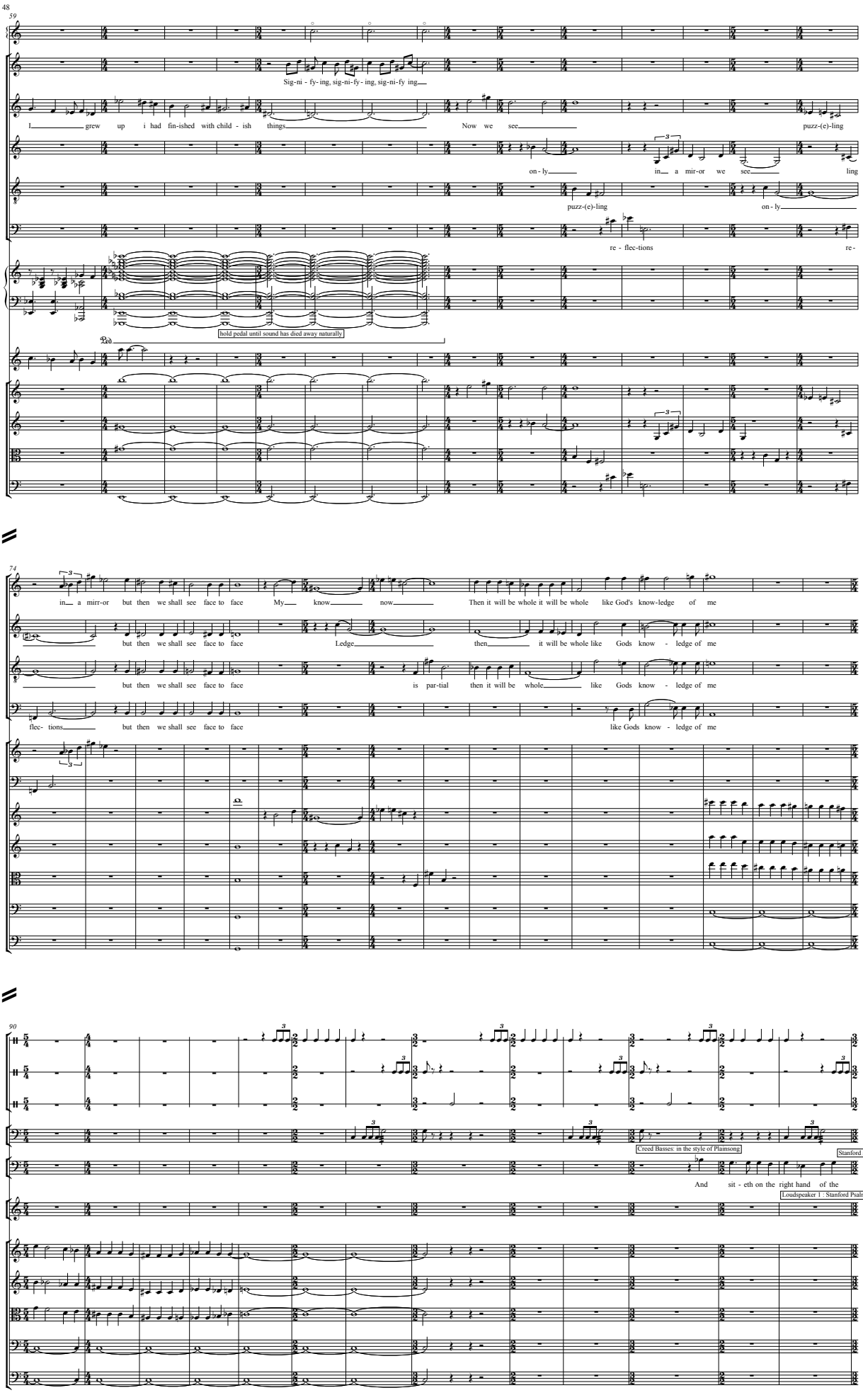

206
S. D.
Tri.
B. D.
Gong
Timp.
S.
faith it's hope its en - dur - ance
A.
to it's faith it's hope it's en - dur - ance
T.
lim - it to it's en - dur - ance
B.
no lim - it to it's en - dur - ance
Vln I
Vln II
Vla
Vc
Vln. I qrt
div
unis
Vln. II qrt
Vla. qrt
Vc. qrt
Cb.

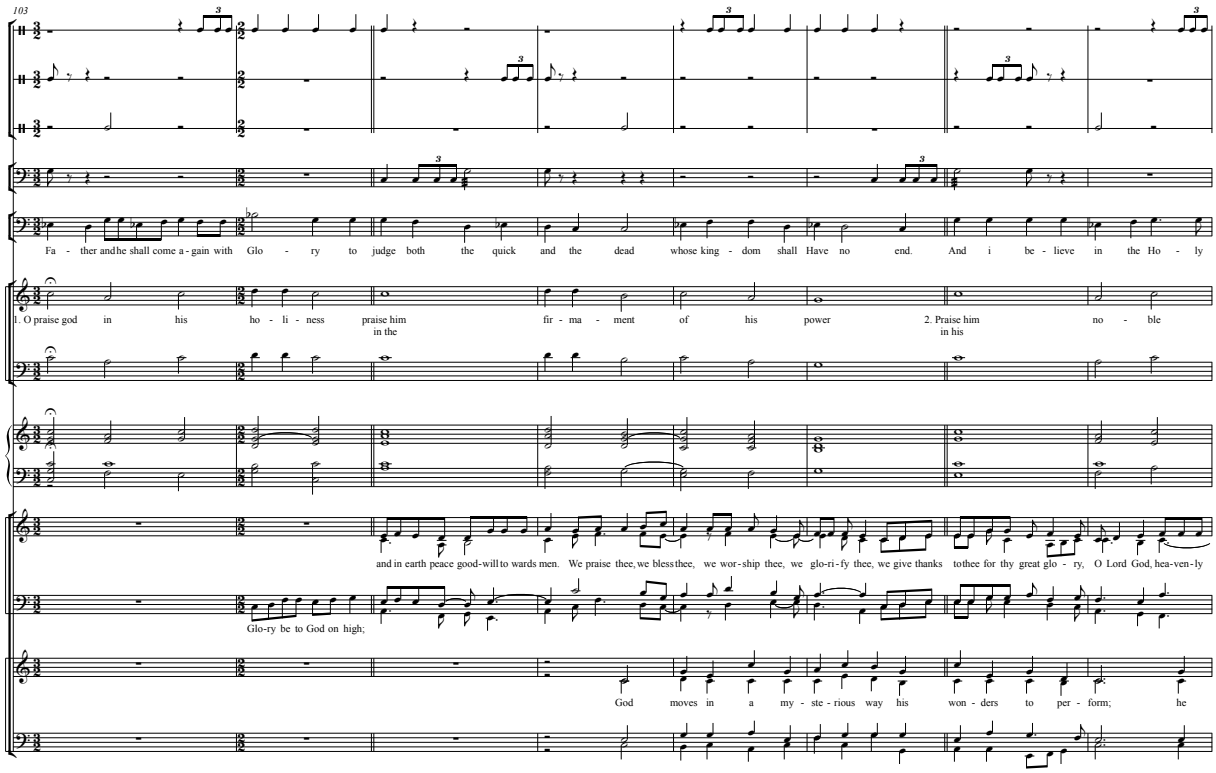

214
S. D.
Tri.
B. D.
Gong
Fl.
S.
It is Fin - ish - sh - 'd
A.
It is Fin - ish - sh - 'd
T.
It is Fin - ish - sh - 'd
B.
It is Fin - ish - sh - 'd
ponticelli trem
Pizz
Vln I
Vln II
Vla
Vc
219
Fl.
Hp.
S. Solo
It is a tale told by man i - - - - - di - ot sig - ni - fy - ing

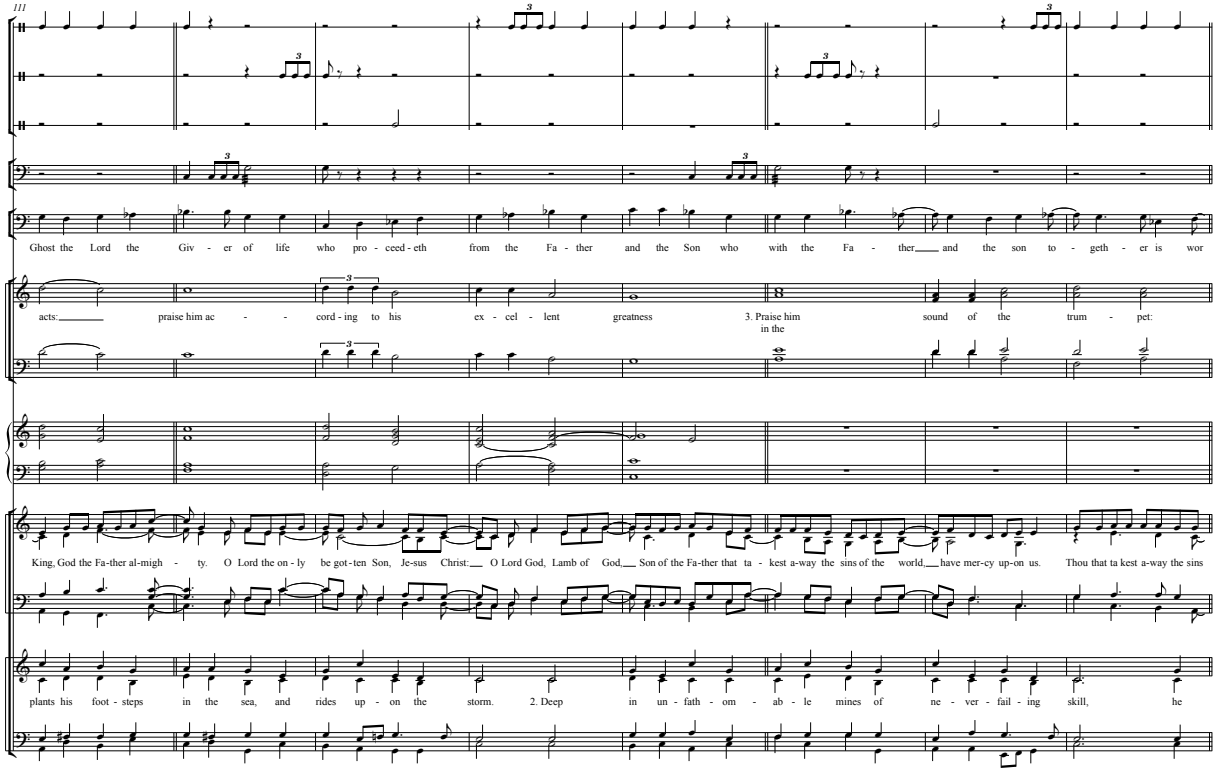
Tertia Pars

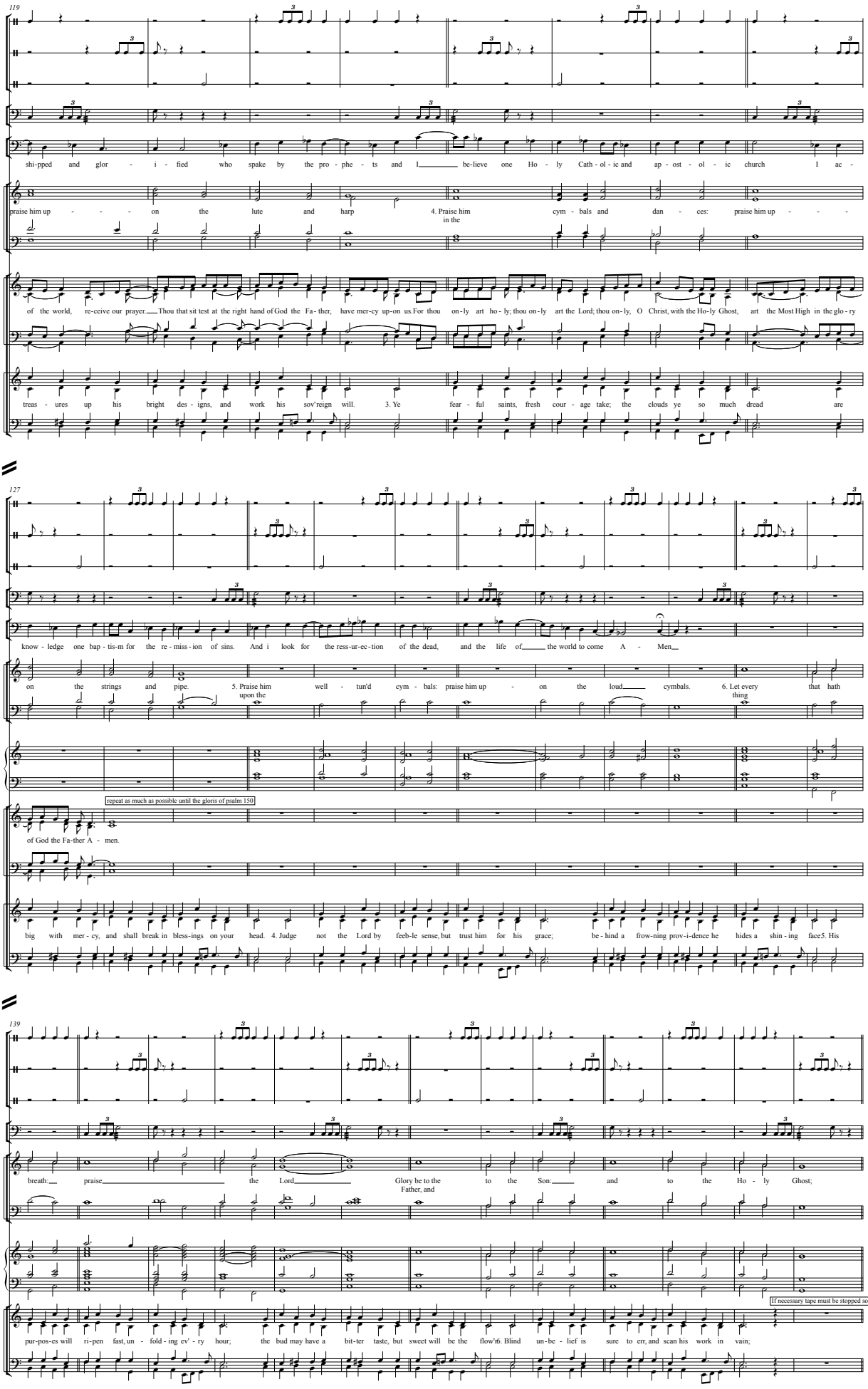
Gregory Clifton-Smith

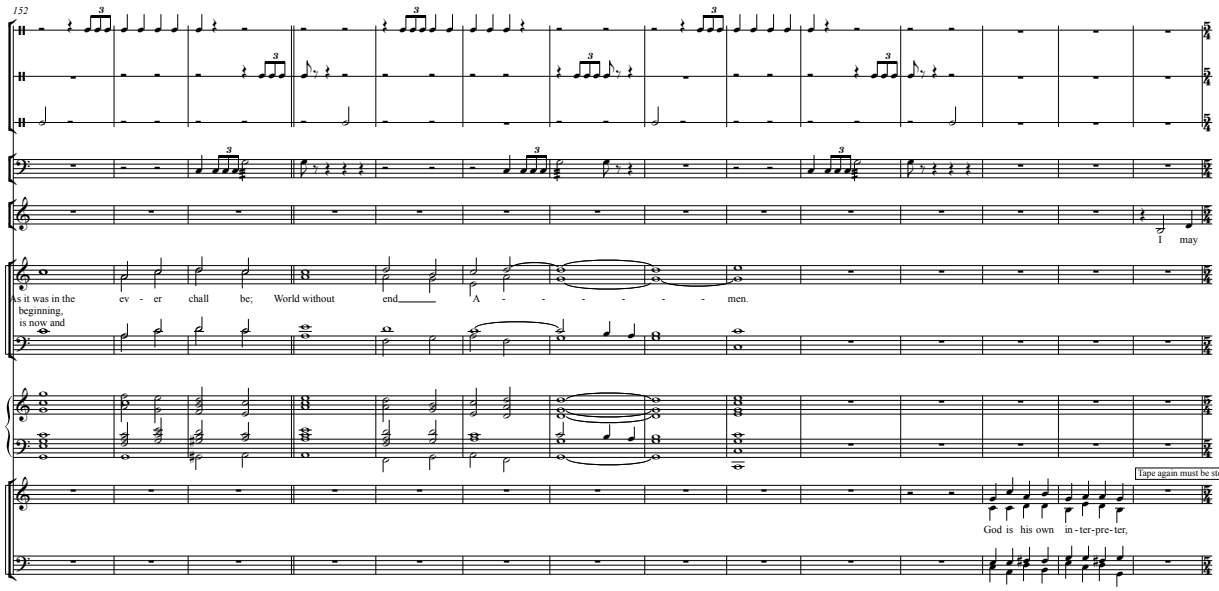


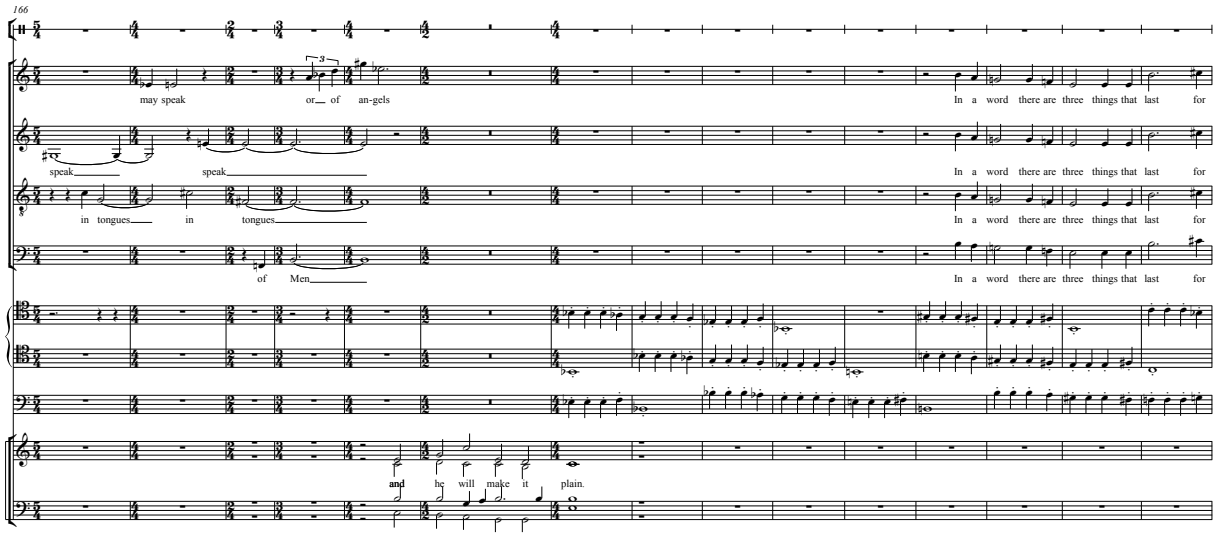

59
Sig-ni - fy- ing, sig-ni-fy - ing, sig-ni-fy ing
I grew up i had fin-ished with child - ish things
Now we see
puzz-(e)-ling
on - ly
in a mir-or we see
puzz-(e)-ling
on - ly
re - flec-tions
re -
hold pedal until sound has died away naturally
74
in a mirr-or but then we shall see face to face
My know now
Then it will be whole it will be whole like God's know-ledge of me
but then we shall see face to face
Ledge
then
it will be whole like Gods know - ledge of me
but then we shall see face to face
is par-tial
then it will be whole
like Gods know - ledge of me
flec- tions
but then we shall see face to face
like Gods know - ledge of me
90
Creed Basses: in the style of Plainsong
Stanford at the hilpoint of 'And' sung by the cre
And sit - eth on the right hand of the
Loudspeaker 1 : Stanford Psalm 150

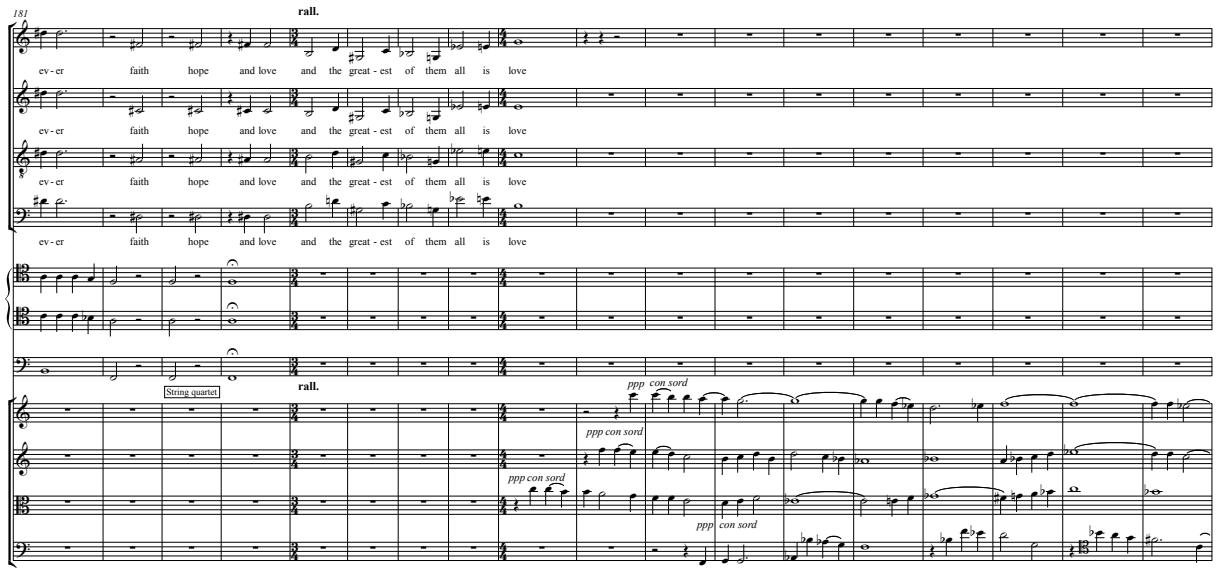

103
Fa - ther and he shall come a - gain with Glo - ry to judge both the quick and the dead whose king - dom shall Have no end. And i be - lieve in the Ho - ly
1. O praise god in his ho - li - ness praise him in the fir - ma - ment of his power 2. Praise him in his no - ble
and in earth peace good-will to wards men. We praise thee, we bless thee, we wor-ship thee, we glo-ri-fy thee, we give thanks to thee for thy great glo - ry, O Lord God, hea-ven-ly
Glo-ry be to God on high;
God moves in a my - ste - rious way his won - ders to per - form; he

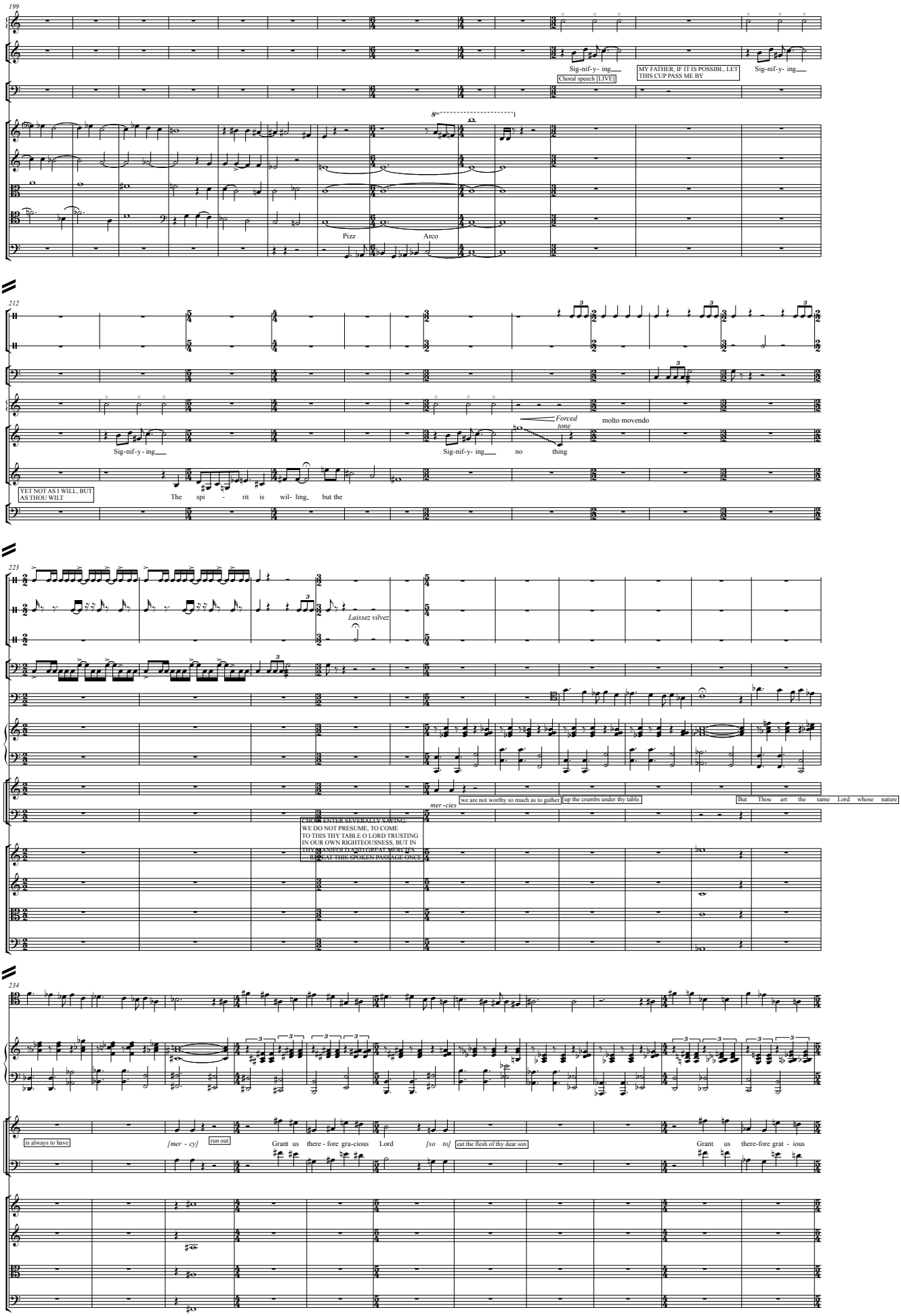

111
Ghost the Lord the Giv - er of life who pro - ceed - eth from the Fa - ther and the Son who with the Fa - ther, and the son to - geth - er is wor
acts: praise him ac - - cord - ing to his ex - cel - lent greatness 3. Praise him in the sound of the trum - pet:
King, God the Fa-ther al-migh - ty. O Lord the on - ly be got - ten Son, Je-sus Christ: O Lord God, Lamb of God, Son of the Fa-ther that ta - kest a-way the sins of the world, have mer-cy up-on us. Thou that ta kest a-way the sins
plants his foot - steps in the sea, and rides up - on the storm. 2. Deep in un - fath - om - ab - le mines of ne - ver - fail - ing skill, he

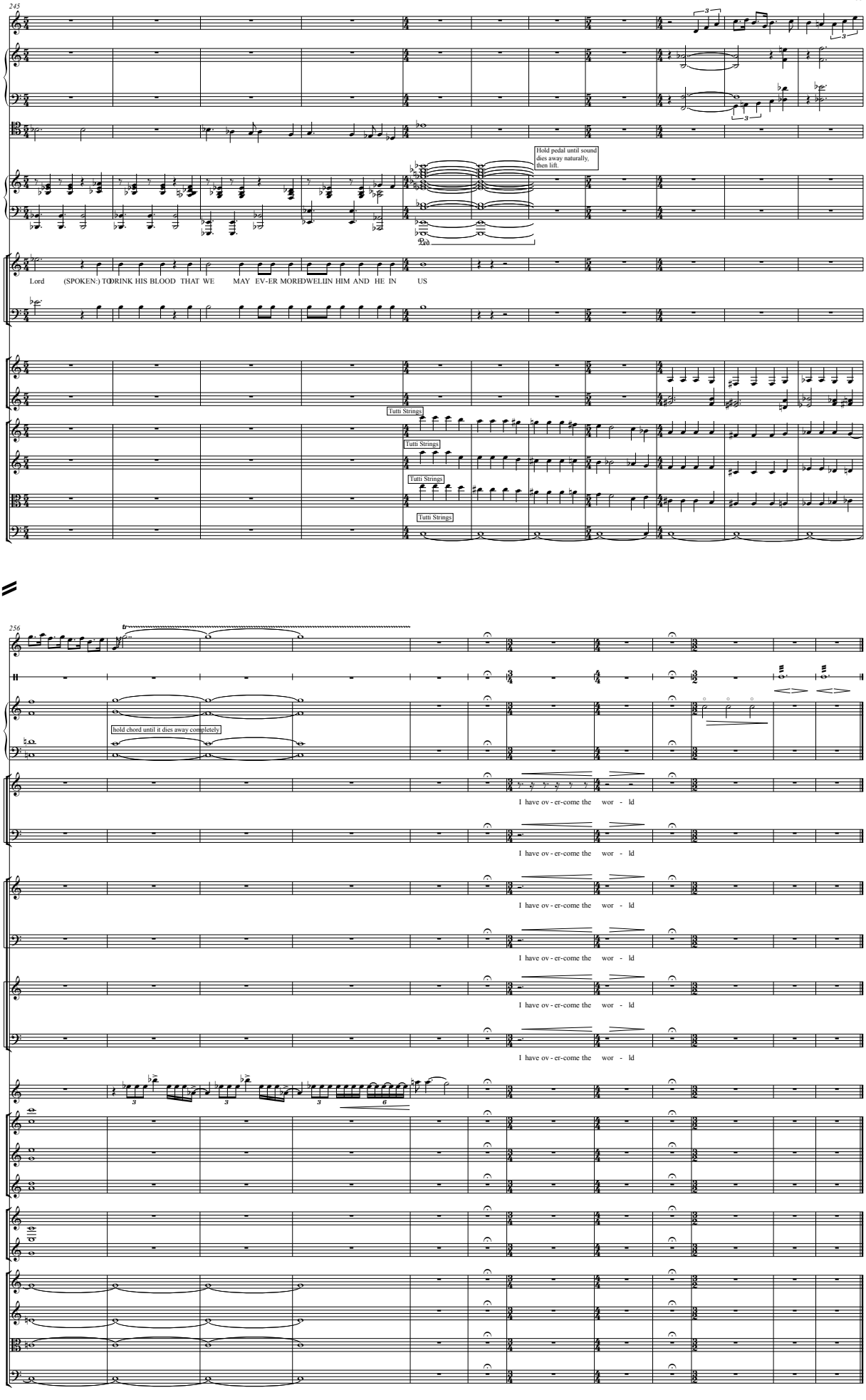

119
shi-pped and glor - i - fied who spake by the pro - phe - ts and I be-lieve one Ho - ly Cath - ol - ic and ap - ost - ol - ic church I ac -
praise him up - - - on the lute and harp 4. Praise him in the cym - bals and dan - ces: praise him up - - -
of the world, re-ceive our prayer. Thou that sit test at the right hand of God the Fa - ther, have mer-cy up-on us. For thou on - ly art ho - ly; thou on - ly art the Lord; thou on - ly, O Christ, with the Ho-ly Ghost, art the Most High in the glo - ry
treas - ures up his bright des - igns, and work his sov'reign will. 3. Ye fear - ful saints, fresh cour - age take; the clouds ye so much dread are
127
know - ledge one bap - tis-m for the re - miss - ion of sins. And i look for the ress-ur-ec - tion of the dead, and the life of the world to come A - Men.
on the strings and pipe. 5. Praise him upon the well - tun'd cym - bals: praise him up - on the loud cymbals. 6. Let every thing that hath
repeat as much as possible until the gloris of psalm 150
of God the Fa-ther A - men.
big with mer - cy, and shall break in bless-ings on your head. 4. Judge not the Lord by feeb-le sense, but trust him for his grace; be - hind a frow-ning prov-i-dence he hides a shin - ing face5. His
139
breath: praise the Lord Glory be to the Father, and to the Son: and to the Ho - ly Ghost;
pur-pos-es will ri-pen fast, un - fold - ing ev' - ry hour; the bud may have a bit-ter taste, but sweet will be the flow'r6. Blind un-be - lief is sure to err, and scan his work in vain;
If necessary tape must be stopped so as to attain correct coordination with t


152
I may
As it was in the beginning, is now and ev - er chall be; World without end A - - - - - - men.
Tape again must be stopped so that at its next entry corect co
God is his own in - ter - pre - ter,


166
may speak or of an-gels In a word there are three things that last for
speak speak In a word there are three things that last for
in tongues in tongues In a word there are three things that last for
of Men In a word there are three things that last for
and he will make it plain.


181
rall.
ev - er faith hope and love and the great - est of them all is love
ev - er faith hope and love and the great - est of them all is love
ev - er faith hope and love and the great - est of them all is love
ev - er faith hope and love and the great - est of them all is love
String quartet
rall.
ppp con sord
ppp con sord
ppp con sord
ppp con sord


199
Sig-nif-y- ing
Choral speech [LIVE]
MY FATHER, IF IT IS POSSIBL, LET THIS CUP PASS ME BY
Sig-nif-y- ing
Pizz
Arco
212
Forced tone
molto movendo
Sig-nif-y - ing
Sig-nif-y- ing
no
thing
YET NOT AS I WILL, BUT AS THOU WILT
The spi - rit is wil- ling but the
223
Laissez vilvez
mer -cies
we are not worthy so much as to gather up the crumbs under thy table.
But Thou art the same Lord whose nature
CHOIR ENTER SILVERALLY SAYING:
WE DO NOT PRESUME, TO COME
TO THIS THY TABLE O LORD TRUSTING
IN OUR OWN RIGHTEOUSNESS, BUT IN
THY MANIFOLD AND GREAT MERCIES
REPEAT THIS SPOKEN PASSAGE ONCE
234
is always to have
[mer - cy]
run out
Grant us there - fore gra-cious Lord
[so to]
eat the flesh of thy dear son
Grant us there-fore grat - ious


245
Hold pedal until sound dies away naturally, then lift.
Lord (SPOKEN:) TO DRINK HIS BLOOD THAT WE MAY EV-ER MORE DWELL IN HIM AND HE IN US
Tutti Strings
Tutti Strings
Tutti Strings
Tutti Strings
256
hold chord until it dies away completely
I have ov - er-come the wor - ld
I have ov - er-come the wor - ld
I have ov - er-come the wor - ld
I have ov - er-come the wor - ld
I have ov - er-come the wor - ld

Texts and musical quotations used in 'Collage'

Texts.

1 The Collect for Purity & The Prayer of Humble Access.

The Book of Common Prayer. (pp 142, 152) Cambridge, United Kingdom: Cambridge University Press.

2 1 Corinthians 13 [AV].

3 The 'Tomorrow and tomorrow and tomorrow' speech from Shakespeare's 'Macbeth'. Act V Scene V

Craig, W. J. (Ed) (1966). *The Oxford Shakespeare Complete Works.* London, United Kingdom: Oxford University Press.

4 An account of drug withdrawal by Peter Laurie.

Laurie, P. (1967). *Drugs - Medical, Psychological, and Social Facts.* (pp.21, 23 -24.) Harmondsworth, United Kingdom: Penguin Books.

5 Mathew 26:39 [AV].

6 John 16:33 [AV].

Texts and musical examples.

7 Setting of the words of the Creed.

8 Setting of the words of the Gloria.

Merbecke *Office of Holy Communion (1568)* G.H Knight (Ed) United Kingdom: RSCM, SPCK

9 Stanford, C. V. Psalm 150. *English Hymnal No. 390*

10 Tune London New C.M (Music from the Scottish Psalter (1635) adapted by John Playford); Text Cowper, W. God moves in a mysterious way. *Hymns Old and New (Anglican Edition) No. 173*